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CARE OF INSTITUTIONALIZED MENTALLY DISABLED PERSONS

JOINT HEARINGS

BEFORE THE

SUBCOMMITTEE ON THE HANDICAPPED

OF THE

COMMITTEE ON

LABOR AND HUMAN RESOURCES

AND THE

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES SENATE

NINETY-NINTH CONGRESS

FIRST SESSION

ON

EXAMINING THE ISSUES RELATED TO THE CARE AND TREATMENT OF THE NATION'S INSTITUTIONALIZED MENTALLY DISABLED PERSONS

APRIL 1-3, 1985

PART 2

APPENDIX: STAFF REPORT ON THE INSTITUTIONALIZED MENTALLY DISABLED

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APPENDIX

STAFF REPORT ON THE INSTITUTIONALIZED MENTALLY DISABLED

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STAFF REPORT ON THE INSTITUTIONALIZED MENTALLY DISABLED

REQUESTED BY SENATOR LOWELL P. WEICKER, JR.

Prepared for Joint Hearings Conducted by the

Subcommittee on the Handicapped
Committee on Labor and Human Resources

and the

Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
Committee on Appropriations

April 1-3, 1985

Executive Summary

On too many wards of state facilities for the mentally disabled, residents and staff exist in a climate of fear and intimidation. And despite the regular outside scrutiny of, at best, only a handful of state-paid monitors -- whose internal reporting, however aggressive, is largely denied public airing -- these residents and employees live and work in virtual secrecy.

Conditions in many of these facilities, especially psychiatric hospitals, where some of society's most severely disabled patients live in a volatile daily mix with some of the health-care profession's most undertrained staff, would be considered intolerable if this airing was full and frequent.

Senate staff has found that on many wards, patients and residents are vulnerable to abuse and serious physical injury. Documented incidents in facilities visited by the staff include kicking or otherwise striking patients, sexual advances and rape, verbal threats of injury and other forms of intimidation. Milder forms of verbal harassment are seen as an important method for controlling potentially violent or aggressive patients and residents.

Another frequent method of control is restraint and/or seclusion. Patients of state facilities for the mentally ill and residents of state institutions for the mentally retarded are frequently subject to periods of forced isolation as a method to control behavior. A wide variety of mechanical restraints are

also available to staff, designed to prevent injuries. Especially with highly agitated psychiatric patients, these restraint procedures are often dangerous tests of strength and the episodes are openly feared by staff and patients alike.

There is little treatment other than medication provided in many state institutions according to staff, patients and advocates interviewed by Senate staff. The great majority of state psychiatric patients on all wards visited by Senate staff are given some form of medication, many on an "as needed" basis as determined by direct-care staff. The general lack of activity tolerated in many state institutions visited by Senate staff leaves the ward dayrooms as the focus of patient and staff activity. Medications and mechanical restraints are often the only alternative or backup in direct-care staff attempts to maintain control.

Where injuries are reported, staff injury rates are generally higher than those of patients. The direct-care staff see their injuries as a product of low staffing, new and tougher patients, and lack of off-ward activities.

Many facilities visited by Senate staff fail to maintain decent living conditions. Many wards sleep patients/residents in long dormitories in beds several feet apart. As many as half the patients in some wards have no closet or private storage space. Lack of privacy in toilet and shower areas is often due to poor repair, with doors and curtains removed. Some facilities have no apparent internal standards, as several wards may appear barren

and in disrepair with the smell of urine and cigarette smoke in the air and patients sleeping on bathroom floors, while another ward can appear clean and well-equipped, the patients engaged in minimal programming like exercise or discussing current events.

State systems for monitoring facility compliance with patient rights and seeking improvement of conditions vary widely. Federal funding for the protection and advocacy of mentally ill persons was once authorized by Congress (as it has been for the mentally retarded). But that authorization, along with an enforceable bill of rights for the mentally ill, was repealed by subsequent legislation.

Many of the nation's state psychiatric facilities are voluntarily subject to review by the private Joint Commission on Accreditation of Hospitals (JCAH). These reviews, which are frequently a determining factor in whether federal funds may be received by a facility with a passing grade, are an uncertain test of a facility's level of care and treatment of the mentally ill. Largely focused on paperwork requirements, the JCAH reviews occur at regularly scheduled intervals and are considered predictable by hospital personnel.

Psychiatric facilities participating in the Medicare and Medicaid programs are subject to review by the Health Care Financing Administration (HCFA) of the Department of Health and Human Services (HHS). There are a number of weaknesses in this process with the potential to adversely affect patient health and safety. States largely certify their own eligibility for federal

money, subject to infrequent audits by the Health Care Financing Administration. When deficiencies are found, there are no federally-mandated deadlines for correction. A facility able to demonstrate progress toward correcting deficiencies is rarely decertified, even if agreed-upon deadlines are not met.

While the federal government spends approximately $2.5 billion on institutions for the mentally retarded and has established a comprehensive certification process to ensure compliance with over 600 standards, many residents of these institutions do not receive, in some cases, even minimal services and care. As in participating psychiatric facilities, states largely certify their own institutions for the mentally retarded, subject to a federal "look-behind" audit. But these audits are infrequent and more importantly, do not ensure timely correction of policy or practice when deficiencies are identified. Neither does the certification process address the issue of institutional residents appropriate for community placement. There is no formal or informal mechanism by which the Department of Health and Human Services and the Department of Justice share information, coordinate activities, or make referrals, although the agencies have clearly complementary responsibilities under federal law.

The U.S. Department of Justice continues to play a limited role in monitoring conditions in facilities for the mentally disabled as they relate to constitutional and federal statutory requirements. The few investigations commenced by the Department's Office of Civil Rights suggests a continuation of

the inactivity noted in previous congressional testimony. Further, recently concluded investigations show that the Department's notice to the states as to findings have been sent up to 27 months after the investigations were initiated. The Department's lack of timeliness and consistently conciliatory approach in the face of conditions determined to be egregious and flagrant abuses of the institutionalized mentally disabled, allows these conditions to fester, distorting the purpose of congressionally mandated intervention.

State hospital admissions are no longer decreasing nationwide, partially because the population at risk for certain psychiatric disorders is on the rise. At a time when outpatient alternatives are overburdened and underfunded, the stage is set for a new era of institutionalization and an even greater role for hospital wards.

The findings of this investigation demand change. Abuse and neglect of society's most vulnerable citizens must stop. Care and treatment must be provided in an atmosphere of dignity and respect. And those to whom this care is entrusted must be held fully accountable.

Introduction

Over the course of several months, Senate staff travelled to 12 states and examined documents and interviewed individuals from several other states regarding environmental conditions and physical health and safety in state mental hospitals and, to a lesser extent, state facilities for the mentally retarded.

As part of this review, Senate staff visited 31 facilities and conducted an estimated 600 interviews with staff, patients of state psychiatric facilities and residents of state facilities for the mentally retarded, facility administrators, state and federal officials and others in the field.

Senate staff visited four institutions under confidential arrangements. These institutions are not identified in this report. However, additional formal and informal Senate staff visits were conducted in the following states and facilities:

CALIFORNIA

Camarillo State Hospital
Fairview State Hospital
Metropolitan State Hospital
Napa State Hospital

COLORADO

Fort Logan Mental Health Center

CONNECTICUT

Connecticut Valley Hospital
Fairfield Hills Hospital
Mansfield Training School
Southbury Training School

GEORGIA

Central State Hospital
Southwestern State Hospital

a) Thomasville Campus
b) Bainbridge Campus

MARYLAND

Springfield Hospital Center
Spring Grove State Hospital

MICHIGAN

Northville Regional Psychiatric Hospital
Ypsilanti Regional Psychiatric Hospital

NEW JERSEY

Trenton Psychiatric Hospital

NEW YORK

Creedmoor Psychiatric Center
Manhattan Psychiatric Center
South Beach Psychiatric Center

PENNSYLVANIA

Polk Development Center
Pennhurst State School
Embreeville Center
Woodhaven Center

TEXAS

Austin State Hospital
Terrell State Hospital

WASHINGTON (Day Treatment Center and Shelter)

Harborview Community Mental Health Center
Downtown Emergency Service Center

In the state psychiatric hospitals visited by Senate staff, the scene was generally the same:

Walking through a series of locked doors onto any of several adult psychiatric wards, the odor of cigarette smoke is pervasive and the stench of urine is often present, as is the television noise from a morning game show, afternoon soap opera or evening sitcom. A new visitor is quickly surrounded by a group of patients with the ever-present questions: "Are you a lawyer? Can you get my doctor? Can you get me out of here? Do you have a cigarette?"

Other patients shuffle away from the commotion, across a dayroom where patients and staff spend most of their days and evenings.

Most patients sit or lay quietly on available surfaces: furniture, including tables, radiator shrouds, window sills and the floor. Some sleep, some stare, others rock steadily in place or pick invisible nits from their hair.

Many patients look fleshy and unkempt, their clothing ill fitting and mismatched. Several talk to themselves, some try to draw others into their delusions forcefully, some protect invisible space around them by cursing at fellow-patient intruders who pace the dayroom continuously end to end. Most sleep or sit quietly.

The glassed gazebo jutting from a wall near the center of the room by a locked door leading to the dormitories, is a nurse's station. Inside, a nurse and/or aide is invariably

filling out paperwork.

One wall of the station is papered with directives and policies from the facility administration and state central office. Another has a locked cabinet of medications and shelf of thick notebooks, one for each patient on the ward.

Another staff person sits with patients at the television, identified only by the keys on his belt and occasional commands to the pacers to move from the line of vision. Another staff person may be the fourth in a gin rummy game with a group of the "higher functioning" patients while at the same time, he consoles a patient with delusional fears who has pulled a chair up next to his.

If these four staff members are lucky, on a psychiatric ward they will have no more than 30 patients in their charge. If they are not, they may have 40 patients. Even in that former, relatively fortunate 7.5-1 ratio, any one of more than a dozen routine responsibilities can pull staff off of regular ward work on a given shift, instantly shifting ratios to 10-1, 15-1 or worse.

Violence is considered a de facto feature of ward life in many facilities, ascribed by staff to the aggressive nature of patients and residents, and by advocates to the lack of training of staff. Although sustained physical abuse of patients/residents has occurred in some facilities and patient-to-patient aggression is considered common, most staff-to-patient physical contact is a matter of ward procedure.

Many patients have PRN prescriptions for psychotropic medication, from the Latin "pro re nata" meaning "as needed". This "need" is often determined by ward staff observations of patients in agitated states. By some estimates, up to two in five patients on medication are subject to an involuntary movement disorder that can be permanent. The disorder, Tardive Dyskinesia, is poorly understood and infrequently monitored.

While these prescriptions are written in advance, other methods of control such as restraint and seclusion of patients can be initiated by ward staff and later approved by physicians. Some monitors have found a link between sudden death of patients and restraint procedures that often involve tying patients to beds in isolation rooms. The level of force required in these procedures varies, but patients and advocates complain consistently that excessive force is often used. Suspected rapes and beatings are reported during and subsequent to the use of these procedures.

Some facilities report a high percentage of unexplained injuries to patients, and Senate staff observed patients with unexplained bruises and cuts and patients seeking protection from other patients.

To avoid more intrusive procedures, ward staff frequently threaten patients with isolation or loss of privileges.

While facilities seek to maintain control, they frequently fail to maintain the basic amenities expected as part of their custodial function. Patients are often lined up and showered in

succession on schedule, sometimes under gang showers without curtains or changing areas. Hand towels, soap and toilet paper can be missing from some ward bathrooms for several days, but plentiful on another ward of the same facility. Some patients sleep in a gymnasium with beds less than three feet apart, others live in dormitories where the lack of closet space forces them to keep their few belongings folded in a paper sack under their bed, at the risk of being stolen by other patients.

When asked, facility administrators and state officials say living conditions are in the process of being corrected. Ward staff, however, take a cynical view of these "plans". In several cases, ward staff said newspaper and television news accounts of these living conditions result in improvements, albeit temporary.

Although there is a general ethic against patient abuse as they narrowly define it, there is a palpable fear among staff on many wards. While most long time staff say the "old days" of staff violence against patients are gone, staff say they are seeing a younger, more aggressive patient, quicker to "go off" and tougher to "take down".

In this atmosphere, the complaints of staff are seen as weights on a scale that tip the delicate ward balance against them: irrelevant paperwork that takes time away from patient interaction; foreign-born doctors who hold broad commitment and medication authority, who rarely interact with patients and who sometimes have an almost tragicomic inability to deal professionally in the English language; a legal system that seems to encourage patients to file complaints against staff and

discourage patients from taking medication; and most often heard, staffing ratios that are too low or assignments that "float" unfamiliar staff together on each shift.

From the patient's perspective, that balance is supposed to be maintained by internal monitoring and investigation of complaints by ombudsmen or patient advocates in the facility's employ. Only a few states provide for outside counsel.

Every hospital has a mechanism for reporting abuse and other incidents on the wards and most have designated employees to act on complaints and report to the facility administration.

But as with any hospital procedure, the policy is only as good as the numbers, authority and ability of those charged with carrying it out.

Residents of facilities for the mentally retarded hold a clear advantage over the institutionalized mentally ill in the area of advocacy to insure their basic civil rights. The federal government has a major role in this advocacy through the funding of Protection and Advocacy agencies in each state. In addition, if the residents are eligible for Medicaid funding the institutions where they live are subject to a certification review by state officials and a potential audit by federal officials from the Department of Health and Human Services.

But these audits are rare and the certification process essentially asks a state to determine its own eligibility for federal money.

In state psychiatric facilities, however, the advocacy process is wholly dependent on state initiative. Congress passed a law in 1980 authorizing funding for advocacy of state mental patients' rights and delineating those rights, but the law was repealed at the time of passage of the Alcohol, Drug Abuse and Mental Health block grant.

Many state hospitals submit to voluntary review by a private accrediting commission that largely bases a passing grade on the hospital's ability to show acceptable paperwork every three years.

In psychiatric hospitals, only persons below the age of 22 and over the age of 64 are eligible for federal Medicaid assistance. Facilities with these populations are also subject to state self-certification reviews. Only five percent of the facilities receive federal "look-behind" audits of these reviews.

The U.S. Justice Department has the authority under the Civil Rights of Institutionalized Persons Act to investigate potentially "egregious and flagrant" violations of the Constitution in facilities for the mentally disabled. Since the law was passed in 1980, however, only 24 investigations have commenced and one lawsuit filed; that occurred in February, 1985.

This combination of federal inaction has left protection and advocacy services for the mentally ill to a patchwork of state and volunteer monitors that vary widely in ability and authority. In one state, volunteers drive hundreds of miles a month to visit institutions and assess such conditions as cleanliness of the

wards and the appearance of residents. In another state, highly-trained investigators conduct regular, systematic, often unannounced reviews of patient and resident care as an independent state agency.

Many states employ staff designated as patient ombudsmen who report to a state central office or the facility administrators. As advocates, these employees are generally designated to respond to specific complaints by patients and staff and have no charge to examine the broad range of patient care issues.

But as a practical matter, even these limited investigations of complaints about abuse or other violence, privileges, property, and other non-medical issues, involve these advocates in a strenuous, ofter adversarial process. Even a successful conclusion to an investigation of one violent incident involves only that incident and does little to address the conditions that make these incidents frequent on many wards.

Too often those whose professional responsibilities and personal efforts include attempts to lessen violence on wards work in virtual isolation. They are feared and disliked by ward staff, intimidated or ignored by the administration and work with law enforcement officials in a shaky, if existent, relationship.

A final inhibitor to violence in many facilities is the media. Accounts of conditions in facilities for the mentally disabled are a staple of investigative reporting in many parts of the country. Staff, patients, advocates and consumer groups frequently have come to rely on exposes in the media to prod

state officials to make changes.

Other forces of change are also having a major impact in psychiatric facilities. Young adults of the so-called baby boom generation are now at the age of highest risk for onset of psychiatric disorders. A high proportion of the homeless are of this generation and considered mentally ill. Indeed, a major focus of the current debate over homelessness involves the proper "mix" of psychiatric care needed, including institutionalization.

The "asylum" movement that pleaded forcefully for custodial care of the mentally ill in the last century has adherents in modified form today. There is a growing call to loosen the standards under which the mentally ill can be involuntarily committed.

Whatever the outcome of this medical, legal and political debate, the fact remains that the census of state psychiatric hospitals is rising again. Predictions are made that the future population of inpatients could rise appreciably in the absence of alternatives, especially in state hospitals for those unable to pay for private care.

Physical abuse of patients and residents in some state facilities for the mentally disabled is a shocking reality. But a more significant reality is that this physical abuse is much less an impulse behavior of ward staff than it is a tragic outcome of ward routines. In their design, these routines are meant to protect patients. In their implementation, they often merely subject patients to situations that should not be tolerated.

The Institution

As a follow-up to a previous review of conditions in Intermediate Care Facilities for the Mentally Retarded (ICFs/MR), Senate staff was asked by United States Senator Lowell Weicker, Jr., to examine issues in state facilities for the mentally disabled, especially psychiatric institutions, that relate to physical health and safety in the facilities and further, to examine mechanisms in place to monitor and prevent institutional abuse and neglect.

Information in the public domain and obtained by Senate staff shows that no level of the current monitoring "system" insures the administration of basic justice, let alone quality care in many institutions for the mentally disabled.

In late September, 1984, a series of allegations of abuse was reported to the Division of Mental Health Advocacy, Department of the Public Advocate, State of New Jersey concerning Trenton Psychiatric Hospital.

The allegations, contained in affidavits, include multiple assaults against patients, including slapping, punching, choking to the point of semi-conciousness, hair-pulling and throwing of patients; verbal threats of severe bodily injury; repeated verbal abuse (i.e. "faggots, creeps, punks"); and excessive force when applying restraints.

The most serious of the allegations concerned a hospital staff member who has since been transferred to another unit. A

hospital official told Senate staff the employee had been transferred because "these wild accusations" were making the employee's job difficult. He said such allegations were frequent and he called patient legal advocates "a disruptive force" at the hospital. One unit of the hospital has denied these state advocates access to ward areas and patient records that detail violent incidents on the wards.

Senate staff also heard allegations that deceptive procedures were employed by hospital officials in the facility's successful effort recently to obtain accreditation by the Joint Commission on Accreditation of Hospitals.

Hospital personnel have alleged a systematic moving of patients off the grounds of the hospital and to unseen areas of the hospital to keep the high level of inactivity from the eyes of reviewers. They further allege that individual patient charts were removed from nurses' stations so as to be unavailable for review. Other staff were allegedly ordered to begin impromptu, unprecedented "classes" on certain wards for patients, but actually for the benefit of reviewers.

Senate staff has also obtained copies of New Jersey's own periodic medical review for the hospital. This review is a self-certification to receive Medicaid funds. In the 1983 review, a state panel found nursing services at the hospital "totally non-complaint in the implementation of the medical regimen."

In the 1984 review, the panel states "nursing services have

deteriorated to such a degree that care does not meet minimally accepted standards."

An investigation by a team of reporters during 1984 published in the Santa Fe (NM) Reporter, revealed a number of allegations, including the following, concerning New Mexico State Hospital at Las Vegas.

--An elderly woman died in July 1984 after part of a temperature-measuring device was allegedly left in her rectum by mistake, blocking her bowel movements; when it was finally removed, she went into shock and died shortly afterward.

--A 63-year-old woman died in February 1984 of "pneumonia," after threatening to commit suicide by self-induced vomiting. Before the fatal incident, she had been placed in seclusion in an unpadded room and had thrown herself against the walls. Upon viewing the body, her son said: "It was real sloppy care. Mom had bruises all over her face."

--In several cases, "pneumonia" was listed as the cause of death of patients who allegedly had gastric tubes slip from their stomachs into their lungs due to negligent care. Other patients who died of "pneumonia" had been left in cold rooms with windows open and inadequate bedcovers. In the words of one nurse: "They are dying of exposure."

--Despite their right to have professional witnesses in

their behalf, only 12 of the last 3,000 people committed to the state hospital have had such witnesses.

--An audit in 1984 revealed that more than 10 percent of the hospital's current psychiatric patients did not have up-to-date legal papers authorizing their commitment.

--Beginning in 1979 and continuing to last summer, state officials received numerous reports of abuse at the hospital from individual staff members, groups of staff, anonymous sources, and two special investigators. The reporters documented that in each month of 1984 through August, state officials learned in increasing detail of abuse and neglect in the facility through internal investigations and clinical audit. In August, the reporters interviewed the state's top health official and apprised him of their findings. The state then initiated its first official, public investigation of the hospital. The head of the state-appointed panel defended his decision not to "name names" or otherwise assess blame for deficiencies found in the 12-day investigation: "Do you think it's easy for me to write this kind of report? I, too, feel deep concerns about the hospital, but is was also important for us to keep our credibility in the government."

In February, 1981, a deaf-mute patient at Northville Regional Psychiatric Center in Michigan died, apparently strangled, while being restrained. A nurse had reported the

patient "acting up" and aides converged on the man to strip him in preparation for being placed in seclusion. During this procedure he was given an injection of medication and later found dead. State police investigation results were turned over to prosecutors, who denied warrants on criminal charges. Several aides were referred for counseling and further training in physical restraint. The nurse was allowed to resign.

The death was one of a series of unexplained or suspicious deaths or suicides revealed in a copyrighted report by the Detroit News following a three month investigation in 1982-1983.

In April 1981, a patient died while in a coma following an escape attempt. Several weeks earlier, the patient had been found in a Northville seclusion room, lying in a pool of blood. The patient's father visited his son at the hospital and told the News, "He had a lot of cuts on his face and a tooth was missing. I don't see how he could get a lot of cuts in a hospital seclusion cell. He told me he was beaten up. He was really frightened. He said they were going to kill him." Two hospital direct-care workers named in the incident were fired but later reinstated. "This is frustrating to everyone," the state's mental health director told the News. "One of the problems throughout the system is the ability to develop a case that will stand the test of arbitration hearings and the due process issue."

In July 1981, a patient died while in a coma after being placed in seclusion. The patient's attorney told the News an autopsy concluded the cause of death was strangulation, noting

throat marks and bruises "indicating excessive force had been used in restraining" the patient.

The state police has reportedly investigated more than 40 suspected rapes at Northville since 1981. One aide has been convicted of three rapes and jailed, but police say "99 percent" of the cases involve patient-to-patient contact.

On Nov. 15, 1982, the U.S. Justice Department began a formal investigation of Northville.

In November 1984, Senate staff observed basement areas of the hospital accessible to patients where staff-to-patient and patient-to-patient sexual contact has been documented and reported to authorities. State investigators said prostitution in return for minor personal items and amounts of money has occurred.

Senate staff also observed a "blind spot" on one ward where two suicide attempts have been made since December 1983. Despite reports to hospital officials, no correction was made.

Staff and administration alike openly consider their facility as the dumping ground for Detroit's most aggressive and difficult young patients.

The hospital has no official capacity and as a result, some 30 people a night sleep in the hospital gymnasium. Some wards sleep patients in dayrooms and beds have sometimes been placed in halls. The overcrowding sustains a high level of tension and staff say PRN, "as needed" medications are used frequently to

control patients.

Senate staff observed instances of 25-1 staffing on adult male wards. In two cases, Senate staff observed patients in dayrooms maintaining a "vigil" behind a large table, kept there, said the aide in charge of the area, to protect them from beatings by other patients.

Hospital personnel on one ward insisted Senate staff privately view a young patient who "doesn't belong here." The man had serious difficulty walking and using his arms. His head remained cocked and his voice was loud and incoherent. "One of the doctors said he's got cerebral palsy," a ward staff member said. The patient had several bruises and recent cuts on his face, head and arms. The staff said the patient was frequently beaten on the ward because "he can't get out of the way of other patients fast enough."

On one ward, a charge aide in her forties who was one of two staff for 35 male patients on the day shift, spoke to Senate staff of her fear on the ward. She said there was nothing for the patients to do and not enough staff. She complained that the inactivity made the men restless and that the medications were not powerful enough. She said the staff had nicknamed the ward "Dodge City."

In February, 1985, the Justice Department notified the state of its findings of conditions that "threaten the health and safety of patients." The notification further stated that "our attorneys will be contacting your office shortly to discuss this

matter further."

A 35-year-old female patient in a locked, all-female ward at South Carolina State Hospital suffered a fatal seizure between 3 and 4 p.m. January 15, 1984. At the time of her death she had lain tied to a bed in full restraint for 13 hours and her clothing was soaked with her own urine.

An autopsy later revealed traces of substances found in semen in her vagina and pubic hairs that were not hers in her restraining suit. Technicians determined the patient may not have been given her regular anti-seizure medication while in restraint. Last August, 11 indictments were handed up against current and former employees of the hospital on charges of patient abuse and neglect. Four of the indictments were related to the above case, two related to the accidental choking death of a patient, and four to an alleged beating of a patient.

In November, 1984, the results of a U.S. Justice Department investigation were made public by the State Department of Mental Health. Justice found serious deficiencies in the number of qualified physicians and nurses, insufficient safety procedures for dangerous patients, inadequately trained doctors, questionable drug prescriptions and improper restraints.

The U.S. attorney for South Carolina said the Justice investigation began in October 1983 after an unnamed citizen

complained of abuse at the state hospital adolescent unit. Eight months previous to that, the state had been sued by a group of adolescents whose allegations included reports of patients made to lay in their own feces in restraint for up to three days. The suit was filed as three separate investigations by state agencies were underway and a month after the unit's director had been fired.

South Carolina Senator Arthur Ravenel, R-Charleston, told Senate staff he "had to beg Brad Reynolds for a year" to involve the Justice Department in the South Carolina situation. Ravenel said Justice Department attorneys seemed "afraid of their boss", Reynolds. After months of attempting to contact Reynolds, Ravenel called Senator Strom Thurmond, R-South Carolina. "Then we got some action," Ravenel said.

The foregoing graphic examples represent elements of a pervasive lack of accountability observed by Senate staff in facilities for the mentally disabled throughout the United States.

Over a period of six months, staff was invited to visit a number of facilities and requested access to many others. In no case was a request denied, but on several occasions, access to certain areas of a facility was not allowed.

Many invitations to visit were issued on an unofficial basis and only after a guarantee that Senate staff would keep confidential the facility name and the names of all persons interviewed. The invitations came from various groups and individuals, including a superintendent of a state hospital; the administrator of a facility for the mentally retarded; professional staff; direct-care staff; advocates, and family and friends of patients and residents.

During these visits, Senate staff attempted to gain the broadest access possible to the facilities. This access varied from several wards over a period of three hours to one ward for five days.

The nature and specificity of the information obtained was also varied. After consulting with a group that regularly monitors conditions at both facilities for the mentally ill and facilities for the mentally retarded, Senate staff adopted elements of facility monitoring forms used by citizen advisory boards in two states. In these states, the boards use formal

questionnaires to assess a variety of conditions on selected wards. The conditions include the type and appearance of patient/resident clothing, the availability of toilet articles, linens and personal effects, the type of restraint and seclusion of patients/residents in use during the visit, the general condition of furniture, toilets, showers and sinks, and the type of activity in which the patients/residents and staff are engaged. By using these forms in wards of several facilities, Senate staff gained an understanding of the elementary physical concerns of institutional life.

Further perspectives were gained during visits to wards hosted by advocates, lawyers and professional monitors. Senate staff accompanied many of these individuals on "rounds" of facilities to note their perspective on their mission and the authority behind their jobs.

Psychiatrists, psychologists, social workers and other professionals, including administrators and their staffs, also conducted tours and gave information on institutional problems and potentials from their point of view.

Senate staff also conducted interviews with patients of psychiatric facilities, residents of institutions for the mentally retarded and representatives of consumer organizations composed of ex-patients and residents. Senate staff attempted to observe whatever "programming," "training," "rehabilitation," or "treatment" available.

By far, the greatest amount of time was spent on the wards

of psychiatric facilities interviewing and observing patients and direct-care staff, to whom the mission of the facility is largely left to accomplish.

The Ward Perspective

Direct-care personnel observed and interviewed by Senate staff in psychiatric facilities make very frank assessments of patients' conditions on the ward. Certain patients are described as "burnouts," generally older patients who behave in a way so as to demand very little interaction with staff. Younger patients who exhibit the same quiet and solitary behavior on the ward seem to earn a different reaction from the staff. These patients are generally closer in age to the young 20-30-year-old staff and the reaction is more one of curiosity, sometimes wonderment that such a condition should exist in a person so young. For these patients, staff can frequently cite a personal history, including a key event that caused the patient to "check out" of society.

Still another group of patients is verbal, physically active within the confines of the ward and anxious and insistent in their interactions with staff. The direct-care staff was frequently heard describing these patients as "high," or "nuts". These patients, on many wards, create a constant hum of voices, punctuated by shouts and accusations, and a regular stream of movement. To a certain level, the activity is allowed by the staff, many of whom feel they have an understanding of behaviors considered routine versus those behaviors that could be disruptive.

Patients considered at risk of suicide, escape, acts of violence or those in restraints or some type of seclusion are frequently placed on "close observation" or "one-on-one." In these situations, which generally must be approved by a doctor,

staff members must maintain an arms length or line-of-sight distance from a patient 24 hours a day until the order is lifted. While the staff member is so occupied, he or she is unavailable for regular ward duties. Senate staff has observed wards where these situations have created 20-1, 25-1 ratios of patients to available staff. The latter ratio occurred in a Michigan hospital, where Senate staff observed the single direct-care worker offering cigarettes to one patient in exchange for the patient's help in keeping other patients "cool."

Some staff members at a psychiatric facility in Ohio reportedly try to stay near groups of "friendly" patients as a shield against more aggressive patients. (1)

The staff's sense of being outnumbered and anxious is common on wards visited by Senate staff. Further, there is a sense on the wards that direct-care workers are facing the patients alone. Often, their only real backup is psychotropic medication or mechanical restraints.

Aside from their own classifications of patients' behavior, the direct-care staff generally has spotty knowledge and little need to understand various psychiatric diagnoses. And aside from entering personal observations in patient charts at the end of shifts, direct care staff have little incentive beyond curiosity to understand the work of the medical staff.

There is a high degree of cynicism expressed by direct-care staff in many facilities concerning the work of some medical, legal and administrative staff. This is especially true of the

staff's view of institutional psychiatrists. These psychiatrists, many of whom are foreign medical graduates, are thought by many direct-care workers to have taken institutional jobs because they are unqualified for other psychiatric work. In one hospital visited by Senate staff, the staff psychiatrists had limited licenses, which permitted them to practice only in the institution.

Echoing the comments of other institutional staff, including psychiatrists, the direct-care workers say there is virtually no psychotherapy at state psychiatric facilities. Instead, Senate staff commonly heard institutional psychiatrists referred to as "gatekeepers," whose medical licenses enable them to approve medications and procedures used to handle problem patients, such as restraint and seclusion, and ultimately decide on a patient's release. These issues are also reflected in public accounts of institutional care.

Officials in the Missouri mental health system told the Kansas City Star that foreign medical graduates are a problem in a state where 68 percent of the state's doctors hold degrees from foreign schools.

"'This just drives me crazy,' said William Taylor, chairman of the state's Mental Health Commission, which oversees the department. 'About every time I (go to a state hospital) I meet a doctor I can't understand. It's a big problem. It's scary.'" A superintendent of one of the state hospitals, himself a foreign medical graduate, recalled his own language problem: "'When I started my residency in Topeka, a paranoid

woman was talking to me. She was talking about her husband stepping out on her. I thought he must have been a crazy man, stepping on her toes.'" The newspaper reported that, "Several persons familiar with the state's mental health system have similar concerns about such doctors treating disoriented patients with whom communication is difficult." (2)

A former state hospital patient in Michigan, where 55 percent of the state doctors are foreign born, related his experience with a foreign medical graduate to the Ann Arbor News. "'You can't talk to them. If they don't know what you're talking about, they think you're crazy,' he said. In answer to one of his doctor's questions, he talked about a friend's father's trip to China. Later, she asked him about his own father, who is dead. On his chart, the doctor wrote: 'Patient thinks father has been in China and is deceased at the same time,' according to the patient who saw the chart." The president of the state psychiatric society told the newspaper, "'Now we're left with a profoundly disturbed nucleus of patients and a reduced nursing staff. It's difficult to recruit physicians.'" (3)

In late 1983, 21 of the 25 full-time psychiatrists in Kentucky's state hospital system were foreign medical graduates. In a series of reports in the Louisville Courier-Journal, hospital administrators praised the abilities of the foreign-trained doctors. But Dr. Edward Tyler, medical director of the state's largest community mental health center, complained of the physicians' treatment methods. "Rather than trying to talk out a patient's problems in therapy, Tyler said, some

foreign doctors prefer to control the patient's psychosis through medication. Often that is because the foreign physicians are uneasy dealing with American attitudes, Tyler said. 'We've swung heavily into prescribing pharmaceutical agents rather than trying to help the person adapt to life,' said Tyler..." (4)

Conversely, a California state hospital that maintains a unit for Spanish-speaking patients, employs a Spanish-speaking direct-care and nursing staff on the unit, but has been unable to recruit Spanish-speaking doctors away from better-paying private sector jobs. Staff on the unit said interaction between patients and physicians occurs through translation.

One analysis suggests that, "For a number of years academic training programs have placed a low priority on the treatment of the chronically mentally ill, who constitute the majority of public patients and who do not traditionally respond to insight-oriented psychotherapy." (5)

Perhaps because there appears to be so little psychotherapy in many state institutions, the lack of fluency in English and understanding of American culture on the part of many of the psychiatrists is not considered a critical situation by direct-care staff. Instead, it is often a source of coffee-break and lunchroom humor: a patient who responded "cool" when asked how he felt began receiving more blankets; a patient who said he had previously worked in a kennel was described as believing he had lived with dogs in a tunnel; a black patient with his hair fixed in braids called "corn rows," was described as exhibiting feminine characteristics; a doctor told a patient there were no

trains nearby after the patient said he had been "railroaded" into the hospital.

Variations of these and other language and cultural barriers were heard at several facilities. Clinical directors at two facilities told Senate staff they felt there is a "trend" in the psychiatric profession toward institutional work that is bringing many more American graduates to the facilities. Although this may remedy one area of the direct-care staff's concern, the more significant area of concern involves the lack of regular interaction between psychiatrists and the direct-care staff and psychiatrists and the patients.

Relations between the direct-care staff and other medical professions at the facilities vary widely. On many wards, licensed practical or vocational nurses handle many of the same tasks as the direct-care staff, who are variously classed as mental health workers, mental health aides, residential care aides, psychiatric technicians, etc. Some states continue to allow certain grades of direct-care staff to dispense some medications and the confusion of responsibilities is noted as a source of tension between staff.

Many wards or groups of wards are supervised by registered nurses, a profession that administrators generally acknowledged as in perpetually short supply at many of the facilities visited by Senate staff. The RN's interviewed by Senate staff complain uniformly that they are forced both by regulations and lack of staff to "treat paper, not people." The nurses said as much as half their time on the wards is spent completing paperwork and

that the bulk of their supervisory time is used to ensure that staff adequately documents ward activity for administrators and surveyors. As supervisors, the RNs are frequently expected to assign janitorial chores to direct-care staff. These truly "custodial" chores are a further source of tension between staff.

Psychologists, social workers and various occupational, rehabilitation and activity therapists are considered by direct-care staff to be genuine allies in the care of the patients. Although each of the occupations is seen as in short supply in the facilities, their interactions with patients are generally seen as valuable to the custodial and therapeutic functions of the ward.

Psychologists are seen as providing a socializing function to the patients, providing an outlet for aggression and the tools for interacting with staff and the other patients. Social workers provide the link between the patients and the "free world," as the outside is often called. Social workers' involvement with patients' families and alternative placements and programs are thought to give patients a reason to act appropriately and eventually leave the institution. Therapists, when available, are valued for the "break" they give direct-care staff in the daily involvement with patients. The activities they provide are considered enjoyable by most patients and often require the kind of concerted effort with its attendant rewards that is missing in daily ward life.

To the extent that each of these functions are in place and regularly available, direct-care staff can sense the fit between

their function and the therapeutic goal. Aside from the obvious courage and tenacity exhibited by many of these employees, Senate staff observed regularly the work of direct-care workers who were eager to play a therapeutic role.

Psychiatric patients who exhibited distress or fear on wards visited by Senate staff were sometimes calmed and soothed by ward staff. Many staff members take special pride in their experience and ability to cheer up or "talk down" patients without training of any kind.

Had it not been for one direct-care worker in New York, a man who had been institutionalized most of his life might still be living in a locked shower room, naked, with a single sheet to cover himself. After the staff member threatened to sue the institution on behalf of this resident, services and treatment were provided which have helped him learn to feed and clothe himself; attend day treatment off the institution grounds; and to live, under supervision, with a group of other disabled adults.

In one facility for the mentally retarded, a group of direct-care workers decided that the absence of trained therapists was resulting in some residents losing the ability to hold objects in their hands. The workers developed their own "course" of exercises designed to retain and develop the residents' ability.

Despite the persistence of dedicated individuals, the numbers continue to work against them.

The lack of adequate staff is perhaps the most consistent

complaint of existing personnel, cutting across the lines of diagnosis of patients/residents or the various levels of accreditation achieved by a particular unit.

In three separate institutions for the mentally retarded including the one just mentioned where employees designed the training course, staff were observed feeding residents who were capable of feeding themselves, albeit at a slower pace.

The problem pointed out by staff in each of the cases was the lack of adequate personnel to take this slower pace into account at mealtime. That is, the number of residents per staff, combined with the amount of time available for a particular meal, meant the residents could not be afforded the chance to use self-feeding skills. Instead, the facility staff lifted spoonfuls of food to the residents' mouth as the preceding mouthful was swallowed.

Another area of staff shortages noted consistently by facility staff concerns staff levels on geriatric wards. Senate staff were told by professionals and other supervisory personnel on wards for the aged mentally disabled that the census of these groups is rising in state facilities, presenting ever-greater challenges to staff, especially in nursing care.

Doctors said the medical profile of long-term geriatric patients, especially those in psychiatric facilities, is increasingly similar to nursing home patients. They noted the increase in neurological disorders, frequently Alzheimer's Disease, that bring with them increased behavioral and control

problems to the wards.

The head nurse on one geriatric ward in Connecticut told Senate staff the daily routine of feeding, dressing and cleaning her patients left the staff no time for such activity as helping patients retain the ability to feed, dress and walk themselves.

On one geriatric ward in Michigan, Senate staff observed approximately 25 men sitting and/or sleeping quietly in chairs lining a dayroom. Two of the men cradled toy animals in their arms. In one corner, by the television set, a direct-care worker sat watching, with her arm around a man apparently talking to himself. "They're being good today," she said.

Findings

Senate staff requested a variety of institutional data from approximately half of the institutions visited. (Data was not requested from institutions when Senate staff did not announce their visits or when Senate staff toured a facility with an advocate not employed by the facility.)

A review of the data Senate staff did receive showed vast differences in recordkeeping. As a result, a comparison, and in some cases even a simple evaluation, of data was virtually impossible.

However, the data received did reveal that: On many wards, patients/residents are vulnerable to abuse and serious physical injury.

All of the institutions responding to a request for information documented incidents of patient abuse within the last year which resulted in disciplinary action against staff. The majority of these institutions fired at least one employee. Some employees were allowed to resign with termination charges pending.

Two facilities fired as many as six staff members in 1984 for documented incidents of patient abuse. At one facility, where five people where fired, two staff persons were fired for kicking a patient; two were fired for hitting a patient; and one person was fired for administering an improper injection which resulted in injury to the patient. At another facility, one staff member was fired, and another was removed from the ward,

for improper sexual advances toward a patient.

In December 1984, a staff member at a Connecticut hospital was fired for striking a patient who was in restraints. The employee's union decided to grieve the firing formally at which point, the hospital had to call in authorities for an investigation. The union had agreed to sponsor the grievance because employee witnesses had denied the abuse occurred. Before the investigation began, however, the witnesses acknowledged the abuse and the grievance was dropped.

Union contracts and protections often make it impossible for hospital administrators to actually fire an employee. In lieu of termination an employee may be suspended, demoted, assigned to another unit, or otherwise reprimanded.

During Senate staff visits, hospital administrators frequently expressed frustration with grievance procedures which prohibit employee termination or allow employees to be reinstated after they have been fired. Administrators said they seek to ensure employees a fair hearing and opportunity to respond to hospital allegations, but Senate staff was told of numerous instances of plea bargaining and reduced sanctions even when abuse has been documented. Senate staff was also told that, in one California jurisdiction, it is virtually impossible to get the local district attorney to file criminal charges in substantiated rape allegations if the rape involved a psychiatric patient, whether victim or suspect.

Senate staff was told that patient abuse is far more

frequent than the number of incidents actually reported. At one hospital, a nurse told a Senate staff member that she had specifically requested a transfer to a particular unit where she knew patients were being abused and staff was not reporting it. This nurse has a reputation for reporting abuse and often fears staff retaliation for such action. As a result, the nurse varies her route home to avoid being followed and having her residence identified.

Despite official expectations and no matter how conscientious the direct-care staff, it is unrealistic to expect that staff abuse can be adequately monitored and disciplined by relying on fellow workers as the primary reporters. Aside from strong personal considerations, including loss of effective working relationships and documented threats of retaliation, there are institutional barriers to this sort of freelance monitoring.

During one in-service training session for staff at a facility for the mentally retarded, a staff development officer told the group that the institution "is very strict about abuse." Attending the session was a group of new and longtime staff members. One of the veteran direct-care employees interrupted the session to warn the group that reporting staff abuse of residents could be a difficult undertaking.

"You've got to be two people," the staff member said. "Otherwise you don't have a leg to stand on."

The staff development officer answered that, whether two

people witnessed an incident or not, individuals must report abuse to their supervisors.

But the staff member continued: "Hey, live and learn. I went through it. You do your job and then you're a heel. It's not worth it. I reported it and they said, 'hey, you've got to be two people."

A programming aide at one state hospital (sometime also called a therapist or teacher) told Senate staff she has little faith in the abuse reporting procedures: "(When I see abuse occur) I know I have recourse, I know I can tell my supervisor, and I know I can write a report and try to get a witness to go along with me, but in reality I don't think there is anything that will be done...because of the union being so strong and because I don't think that it is important to the administration. I don't think they really care, unless there's some physical abuse where someone is hurt and their reputation might be at stake. I don't think verbal abuse matters."

Senate staff met with institution monitors and advocates who have observed and reported client abuse. During a visit to an institution for the mentally retarded, one advocate told a Senate staff member she had observed a direct care worker "snatch" a client by the hair, "fling" him into a chair, and "jump" on him to hold him. Earlier that day, the same advocate had observed a direct care worker push the same client across the room into the steel springs of a bed frame. Senate staff later observed this client, naked in a room furnished only with a metal bed frame with wire springs.

In addition to the documented incidents of physical abuse of patients in institutions, many patients suffer serious injuries from other causes.

In some cases, serious injuries to patients have been sustained with no cause reported. At two facilities for the mentally retarded in Connecticut, a third of the serious resident injuries in a one-year period, were reported as having no known cause. Serious injury at these institutions is defined as resulting in fracture, hospitalization, and/or death. In more than half of the serious resident injuries sustained at one Connecticut facility, it was determined that no one was at fault. At one state hospital in Georgia there were 506 patient injuries last year for which the cause was unknown. One hundred seventy-seven of these injuries required attention by the hospital Medical/Surgical unit.

Most hospitals keep extensive records on patient injuries. Some include patient injuries as part of a comprehensive annual incident report; some hospitals note the injuries in individual patient charts; and still others categorize injuries in such a general manner that neither the cause nor extent is discernible.

For those hospitals that clearly document the causes of patient injuries, the number and nature of these injuries reflect an environment which threatens the safety of hospital residents.

Patient-to-patient assaults are a common cause of injury. At one state hospital in California 46 percent of all patient injuries were caused by aggressive acts between patients. At two

other hospitals visited, a third of all patient injuries were caused by other patients.

Senate staff consistently observed cuts and bruises on patients and residents that facility staff explained as patient-to-patient injury.

Another explanation given for observed cuts and bruises was patient self-abuse. Senate staff observed patients and residents who deliberately tried to harm themselves either by intense scratching at parts of the skin, or banging their heads against a wall until facility staff intervened.

In one hospital, Senate staff was told of a patient who had deliberately run, twice, head first, into a hospital wall. The patient subsequently died from the injury.

On a "behavior-modification" unit of a Pennsylvania facility for the mentally retarded, several adolescent and young adult males were observed with reddened and marked faces, arms and hands. Scabs were visible and some of the residents continually fingered or picked at the scabs. A direct-care worker observing these residents called their names and the action caused them to stop briefly. The worker said the residents were "self-stimming," or stimulating themselves, and said the aim of the unit was to stop this behavior.

On the same unit, a resident with similar markings was observed in a seclusion room. Outside the door, a staff member observed the resident through a small porthole and timed the 15-minute seclusion period. Inside, the resident was observed

scraping his head back and forth across a heavy-gauge window screen, his head bloodied. Following the prescribed seclusion period, the resident was removed to the dispensary for brief medical treatment. Staff members said behaviors such as self-abuse, aggression towards staff, urinating and defecating on the floors, and destruction of property, were common on the unit. "They do it to get attention and it works," said one staff member. Two additional rooms on the unit are being converted to seclusion areas, Senate staff was told.

In many of the hospitals Senate staff visited, dormitory and bedroom areas are opened earlier in the evening than hospital policy dictates in order to reduce and minimize tension and aggression on the unit. One unit staff member told Senate staff that the time after dinner and before evening medication can be a particularly "high" or volatile time on the unit. Allowing the patients to move from the crowded hallways and dayroom helps dispel the potential for patient violence and injury.

Another method observed and reported to minimize violence and potential injuries is a separate "secure unit" for the more violent patients. Senate staff visited secure units during their site visits and noted a growing trend toward creating such units. On one secure unit, hospital police are called in to walk through the unit when staff determines there is a dangerously-high potential for violence.

Suicide attempts, Senate staff was told, are considered common in any state institution.

Despite the installation of mirrors, breakaway shower-curtain rods and other ward alterations, there is little confidence that suicide can be prevented. Most wards do not have a full set of any physical barriers to prevent suicide and instead rely on physician orders for constant observation of a patient considered at risk for suicide.

Hospital staff are also at risk of serious physical injury. Last fall, a direct-care worker at a California hospital died following an assault by a patient. After being struck by the patient, the employee fell and suffered a fatal blow to the head. Senate staff visited the facility a short time later and spent an afternoon on a unit where, the previous evening, a hospital staff member had been repeatedly beaten in the head by a patient. A few days earlier, the director of a nearby hospital told Senate staff that violence is the ticket for the mentally ill to be admitted to a state hospital. An official of the union that represents psychiatric technicians (direct-care workers) in the state, said that, at any given time, approximately one in 10 of the technicians is off the job due to a patient-related injury.

Assaults by patients on hospital staff are a fact of ward life in many states. In 1984, 65 percent of all staff injuries at one Connecticut hospital were the result of assaultive behavior by patients. More than half of the 486 staff injuries last year at a Michigan hospital were patient related and approximately one-third of the job injuries reported to the hospital infirmary at one New Jersey hospital were injuries sustained from patient assaults.

While no national figures are available to determine the relative risks of direct-care work, the employees' fear of injury in psychiatric facilities is high. For these employees there is often little more than their own wits or physical abilities to get them safely through the dangerous situations they could face on a given shift on a given ward.

Few direct-care staff said they had been given training in either psychiatric or physical intervention techniques, although such courses exist in some hospitals.

At one hospital, Senate staff attended a three-day course required of all new employees involving a variety of "non-violent" physical techniques for subduing and/or restraining violent patients. The instructor began by stressing that the basis of the techniques was an attitude that the ward staff is supposed to defuse confrontation, not participate. The staff was warned that looking into the eyes of a psychiatric patient could be considered threatening as could a display of tension or fear on the face or body of the staff member.

The physical interventions include a series of blocks, reversals, take-downs, escorts and emergency and restraint procedures. Each of the interventions requires a technique that goes beyond simply learning the physical moves. Blows from patients are supposed to be met with open palms and crossed forearms and deflected; the ward staff was then to back away. Getting a patient to the floor was to be accomplished by sliding the patient's body down the leg of the staff member to a sitting

position. For "escorting" or moving a recalcitrant if not violent patient, the direct-care workers were not to grip the patient, as this is considered confrontational. Instead, the technique calls for keeping the thumb locked against the index finger as you escort the patient, instead of opposing as in a grip.

The instructor said that, above all, ward staff was not to react to patient aggression in kind because it was both illegal and unnecessary. For situations where the staff member's life was in jeopardy, the class was taught in a five-minute demonstration how to jab fingers onto the patients carotid artery to cause a momentary blackout.

On a ward of the same hospital, Senate staff interviewed direct-care workers at length about the non-violent training. Although many praised the facility's effort to provide training, each described in detail situations in their experience that made non-violent interventions impossible.

First, the patient's violence was frequently swift, without warning and seemingly unprovoked. Such acts as punches to the head or blows from behind required the staff to immediately go to the highest level of intervention available. One staff member said "you grab anything you can (on the patient) and hold on," hoping that a nurse would respond quickly with an injection or enough staff would be available to help tie a patient in restraints. Even if the less violent interventions are learned well, there is seldom a chance to practice.

One charge aide supervisor on an adult psychiatric ward in Michigan called it the "code of the west." She explained that "taking a patient down" during an aggressive outburst meant punching or kicking when necessary. Such excessive force is never reported by staff, she said, and is denied if patient complaints lead to an investigation.

In addition to the lack of adequate numbers of personnel to deal with violent situations, there were complaints about the lack of the right kinds of staff. In the lexicon of skills that direct-care workers prize in their colleagues, the highest appears to be the courage to help a fellow worker in a violent confrontation with patients. A second seems to be generally the ability to "read" a patient and determine when the patient is ready to "go off," or "go high."

But the direct-care workers in many facilities say these skills are rated low by the hospital administration. Several hospitals visited by Senate staff routinely move direct-care workers off regularly assigned wards to fill in for absentees. The workers said this "floating" can create a ripple effect of tension, both on the worker's regular and newly-assigned wards. The workers also said the hospital as an organization fails to recognize what the workers believe is the proper mix of male and female staff on the wards. The workers say patients are more easily "talked down" by staff members of the opposite sex and that each ward needs a set percentage of male staff on each shift for violent situations. Forms of intimidation - considered "verbal prompting," but often harsh and threatening - are often

used in violent situations and when assembling some patients for medication or meals.

Many hospital staff do not take any breaks during their shift time for fear of leaving a unit short staffed and in potential jeopardy. Many hospital staff cite frequent and extended absences of hospital employees as a result of injuries sustained on the job.

The review panel formed by U.S. District Court Judge Barefoot Sanders to monitor the Texas mental health system pursuant to a lawsuit, said in 1983, "it is apparent that there is a large amount of violent behavior in the state hospitals."

Violence should be anticipated, the panel said, "because the state hospitals serve patients who become acutely disturbed because of psychoses or who have problems with anger, handling frustration or impulse control. It is the hospitals' responsibility to control the patients' behavior, in order to protect patients from themselves or others, to protect staff, and to provide treatment to reduce the causes of violent behavior. The use of psychotropic medications can be effective in reducing the acute agitation of psychosis, but social treatments are necessary to help patients become more socialized in dealing with anger and frustration, and in developing tolerance and impulse control."

The panel said that at six hospitals, "almost all of the staff's interventions around violent behavior are crisis-oriented and aimed at bringing an already volatile situation under

control. They are therefore reactive rather than proactive and preventive in nature. There is little indication of attempting to develop a therapeutic environment which neither fosters or tolerates violent behavior; and there is little evidence of systematic therapeutic efforts to alter behavior patterns and re-socialize patients."

In its conclusion to the report, the panel said, "There is a general failure to provide individualized treatment programs, there is a high degree of violence among patients, and there is inadequate staffing in the hospitals. These issues appear to be very closely related. Where there is a lack of meaningful programming, there is likely to be higher incidence of unacceptable patient behavior. And where staff is being overwhelmed by the demands of keeping order, it is not surprising that treatment would be relegated to the format of large group programs aimed at the least common denominator in the group." (6)

One year later, after continued monitoring and court-ordered staffing and programming improvements, the panel reported to the court it was "pleased with the emphasis which is being placed upon rapid identification of, and interventions with the development of aggressive behavior."

The panel noted the importance of "structuring the environment to discourage the development of aggressive behavior" and further, wrote, "Several units have recognized that a staff person's fear for their own safety, or comfort or discomfort in handling an aggressive incident may influence the outcome of that incident. Some staff feel more threatened by aggressive acts

than others and the way staff react to incidents can either exacerbate or calm the situation." (7)

A report issued last June by the Governor's Task Force on Health and Safety at Cleveland Psychiatric Institute, cited important "themes" and "impressions" that emerge from discussions with staff and patients:

> "The unsafe atmosphere of the hospital was a theme which appeared and reappeared during much of the Task Force's inquiry. Both patients and staff reported an atmosphere of tension, apprehension and concern for physical safety...An atmosphere of fear, tension, and a sense of futility in getting the sympathetic attention of administration, state officials and the media may make employees feel more like angry victims than health professionals...
>
> "Our impression from talking with staff, patients (and others) is that patient abuse by staff does occur with greater frequency than is reported. Possible causes cited were inexperience and poor training levels of some staff, inadequate screening of prospective employees, and a cautiousness or inability on the part of administration to adequately discipline or dismiss flagrant abusers, as well as the stresses of operating indefinitely under adverse and understaffed conditions...overall one got the feeling of apprehension and concern for safety. When staff themselves share such concerns, the impact on patients, already in an extremely vulnerable state, can be seen to be devastating." (8)

An official at a facility for the mentally retarded in Pennsylvania described the abuse reporting ethic at work there. Officials recently completed an undercover operation at the facility that led to staff members being charged with client abuse. The authorities were alerted only after one staff member related the allegations to the facility superintendent during a clandestine meeting after dark in the facility's parking lot.

In South Carolina, the state Legislative Audit Council has accused the South Carolina Mental Health Department of attempting to cover-up abuse allegations and death reports by failing to forward internal investigations to authorities in violation of state law.

Sufficient staffing, proper training, and frequent monitoring by patient advocates and representatives are all essential to enhancing abuse reporting and increasing prevention of abuse.

Clarence Sundram, Chairman of the New York State Commission on Quality of Care for the Mentally Disabled, has suggested basic strategies for preventing patient abuse that speak directly to the crucial role of direct-care staff.

1. "The task of prevention really begins...with increased attention to the critical role of direct care staff, who have the greatest hands-on contact with patients. Facilities must be allowed to more carefully screen applicants to detect their attitudes toward mentally disabled people and any personal qualities that are relevant to working in the

institutional environment.

2. Once staff are hired, they should be treated as the asset they are. A substantial share of the facility's education and training budget should be devoted to developing direct care employees through training in necessary job skills and in dealing with anger and stress. Emphasis should be placed on dealing with burnout, perhaps through professional conferences with other staff on work-related responsibilities. Employees assistance programs must be available at every institution. Overtime and double shifts should be avoided at all costs because of the toll they take on staff and patient alike.

3. Equally important, professional staff need to be regularly present and available on the wards beyond normal business hours. To reinforce supervisors' obligations toward preventive efforts, investigations of alleged abuse should closely scrutinize the supervisors' responsibility for conditions that may have caused or contributed to an abusive incident.

4. A concerted effort must be made to recruit volunteers to assist staff, particularly during time of greatest pressure on staff energies.

5. Finally, careful consideration should be given to the kinds of staff members assigned to particularly troublesome

wards, such as intensive treatment units for violent male patients."

"Better preventive efforts," Sundram writes, "if they successfully reduce abuse through peer pressure and change the attitudes of staff in state institutions, may lift the veil of secrecy from future incidents. The likelihood of such result will be significantly enhanced if methods are found to protect reporting sources from reprisals, for example, through reassignments of patients or staff, and if investigations and prosecutions are made more effective through the use of independent professional investigations and attorneys." (9)

Living conditions for patients/residents in many state institutions are unacceptable.

Senate staff visited both certified/uncertified and accredited/non-accredited institutions for the mentally disabled. visited accredited and non-accredited state hospitals for the mentally ill. Accreditation and certification standards and procedures are designed to ensure minimal levels of condition and treatment and are discussed at length in a later chapter of this report. However, it is important to note here, that, although certified and accredited facilities for the mentally disabled appear, in general, cleaner and more spacious than uncertified and non-accredited facilities, many of the following conditions were observed in both.

Dormitories and Dayrooms

Bed capacity is often exceeded in both accredited and non-accredited facilities.

At an accredited facility in New York, a unit with a supposed maximum capacity of 30 beds has, at times, accommodated up to 60 patients. At a non-accredited facility in Michigan, some units are so overcrowded they routinely "sleep off" a handful of patients. The patients selected to "sleep off" must either spend the night on another unit or sleep in the hospital gymnasium where beds are set up each night. During the day, dormitories are locked, forcing patients to congregate in the hallways and in the dayroom.

While certified facilities for the mentally retarded limit

the number of residents per bedroom consistent with certification standards, non-certified buildings on the very same grounds often resemble the stark, overcrowded dormitories in the psychiatric hospitals. The director of a Connecticut facility described these differences as a "a dual system," which serves both the "haves" and "have nots".

Sleeping areas rarely contain private closet/storage space for each patient. In some facilities, staff explained that there were not enough wardrobes (unit of drawers, shelf and hanger space) available. On other wards, staff explained that sharing wardrobes was considered acceptable. No matter the number of wardrobes in a sleeping area, patient clothing or personal effects are generally not in evidence. In addition, there are rarely items of furniture beyond beds and wardrobes. Walls are generally bare.

Senate staff observed sleeping areas that accommodated from one to 40 beds and there is generally a relationship between the number of beds and the personalization of a sleeping area. The larger, unpartitioned sleeping areas are generally bare of decorative items or other personal touches. As the size of the area decreases, sometimes through the use of partitions, patients seem to have adopted certain spaces around their beds, with decorations or posters on the walls and more personal effects in the wardrobes. Areas that accommodate one to four persons are generally reserved for patients as an incentive or punishment for their behavior in the group. Several of the areas seemed fully personalized. Many had night tables, with reading lights and

reading material.

A problem noted frequently by patients is the lack of adequate space and security for the personal items they do have. Some patients have locked wardrobes in the sleeping areas with one key each for patient and staff. Some wards have locked closets that are used to store patient items like money, cigarettes, coffee, special clothing, etc. Staff and patients on several wards said staff theft is an occasional problem. Senate staff observed patients at one hospital, on "grounds' pass" visits to a coffee shop, clothing store or recreation area, carrying shopping bags of personal items from their wards for safekeeping.

The use of partitions, often five-foot tall, modular walls, to individualize large sleeping areas is controversial. Advocates support the effect of creating smaller spaces, while staff are often critical, saying the partitions block the view of patients in bed. Senate staff observed areas in partitioned rooms where fires had been set by patients at night. While sleeping areas are generally locked during the day, this was especially true of partitioned areas. Patients, however, seemed to enjoy the effects of partitioned rooms. The dividers created more "corners" where patients could gain some measure of privacy. This is contrasted with the unpartitioned rooms, where sleeping or relaxing patients are often only inches away from others in a tight line of beds.

The largest area of the ward is generally the dayroom, where patients and staff pass the majority of their time. And passing

time is generally an apt description of dayroom activities. The focus of the majority of dayrooms is the television, around which groups of patients and staff are often seen to congregate.

One direct-care staffer, describing dayroom "therapy," said, "We of the General Hospital provide The Guiding Light to The Young and Restless through The Edge of Night," referring to the soap operas that are standard dayroom fare. Most dayrooms lack reading material or board games, although some wards have table games such as ping-pong or pool. Despite the staff cynicism toward "television therapy," it was observed and referred to often as a companion of both patients and staff. Staff seems to value activities that concentrate patients' attention away from staff, away from other patients, and away from unseen, indecipherable impulses or feelings. Television removes the necessity of interaction, but engages patients who function on a variety of levels.

Few other dayroom activities can be so generalized on many wards, where lucid, calm and involved patients live with withdrawn patients or those who are periodically agitated or aggressive. Senate staff observed wards over a period of several days where highly agitated and delusional patients lived with patients admitted for substance abuse as part of their diagnosis and who had recently "binged" to the point of becoming a danger to themselves and/or others.

These latter patients sought out the direct-care staff for more individualized ward activities like card playing, pool or conversation. These activities were consistently interrupted by

more "troubled," apparently lower functioning patients. On several occasions, the disruptions observed by Senate staff resulted in arguments between patients and once, a minor injury to one patient.

Direct-care staff were frequently heard to threaten patients with "time out," a form of seclusion behind an unlocked door, when the patients agitated behavior began to involve staff or other patients.

Mindful of this limited menu of activities the direct-care staff has in the dayroom of many facilities, there is a sort of logic behind the sight of patients in solitary activities like sleeping, smoking, pacing and watching television. From day to day, shift to shift, there are many more possible negative outcomes for staff if they attempt to interact with patients than there are positive outcomes. Personal staff attitudes aside, this is especially true of staff as employees in the hospital organization. There are few rewards in that organization for direct-care staff, whether they interact with patients or not. On the other hand, there are several possible punishments for improper interaction.

Showers and Bathrooms

Many of the shower facilities observed by Senate staff were group showers. Often these showers had no curtains to offer patients any privacy. When curtains were provided they were frequently dirty and moldy and badly in need of replacement.

On one unit in a California hospital, staff was shown a

group shower but was told patients showered individually. In fact, hospital staff said it would be "barbaric" to ask patients to shower together. However, when Senate staff stayed on the ward to observe shower and medication time, all of the 12 women on the ward showered together.

In an accredited facility in New Jersey, Senate staff observed a shower located directly off the dayroom. Hospital staff indicated that a make-shift dressing area with sheets and partitions is erected at shower time.

Bathrooms frequently had no doors on the stalls and toilets that did not flush. These toilets were sometimes filled with feces, urine or vomit. In some hospitals, toilet paper is kept in dispensers in the bathroom. In other hospitals, patients must ask staff for toilet paper, sanitary napkins, and other toilet articles. Senate staff observed bathrooms where sinks were clogged or inoperable, urine was left on the floor and no soap or towels were available. On some units, bathrooms are locked and patients must ask staff for access. Direct-care staff frequently claim that patient behavior prevents the staff from keeping toiletries available.

Senate staff observed bathrooms and shower rooms with no hot water and some with no water at all. On one unit of a California hospital, patients told Senate staff there had not been hot water for days. Hospital staff admitted that this has been a recurrent problem. On another unit in the same hospital, there was hot water but no soap for the showers. Hospital staff said a new supply of soap would probably not arrive for at least a week.

Regulating room temperatures, as well as water temperatures, can also be a problem. Senate staff was told that the units at the California facility were so hot last summer that some patients were treated for heat stroke. Others were sprayed with water through plant sprayers to lower body temperatures.

Conversely, when Senate staff visited a New York psychiatric facility, one unit was so cold patients were not permitted to shower in the morning and wore coats all day on the unit. Hospital staff told Senate staff that cold indoor temperatures are a recurrent problem on winter days.

Senate staff was often told that the units they visited were roach infested. At one hospital in California, staff complained of fly infestation. One Senate staff member was told that when the units at a Connecticut facility were sprayed for roach control, the residents who were lying on the floor were also sprayed. Senate staff observed roaches in New York and Georgia hospitals.

Clothing

With a few exceptions, most of the institutions Senate staff visited provided the residents with state clothing. While some institutions obviously made efforts at individualizing clothing and keeping clothing separate from that of other residents, the majority of facilities stocked underwear, socks, bras, pants, shirts, dresses, etc. in bulk by size and distributed the clothing accordingly. Senate staff routinely observed residents in clothing that did not fit; clothing that was inappropriate for

the time of day and season of the year; and clothing that was torn and soiled. Patients frequently claim their personal clothing, brought in by family and friends, never comes back from the laundry.

Dining Facilities and Meals

Meals in state institutions are provided both on and off residential wards. The abilities and special needs of the facility residents often dictate where and how meals are served. Some meals are served in a separate dining facility, cafeteria style, while others are served on individual trays in a dining area on the ward. Residents who are medically involved or physically disabled, were observed being fed in their rooms and in hallways.

Those who eat in a separate facility are usually accompanied by staff and closely supervised during mealtime. One or two staff members may be left on the unit with the patients/residents who are not ambulatory; who are at risk of running away; who are continually disruptive; or who are in restraint and/or seclusion. Individual meals are prepared and delivered for these residents upon request.

Senate staff visited wards where residents were never permitted off the ward. On one such ward, meals were delivered in large containers and apportioned according to the number of residents. Plastic spoons were the only utensils provided. "Seconds" were supposedly available if desired, but barely enough food had been delivered for everyone to eat once. Approximately

three residents chose not to eat dinner that evening and their meals were offered to the other residents on a first come first serve basis. Mealtime on this unit of 43 men lasted 20 minutes.

Dining facilities off the unit were consistently large, noisy, and sparsely decorated. Senate staff did observe dining areas with tablecloths, and in one case plastic floral arrangements, but these areas were rare.

Mealtime at a Pennsylvania facility for the mentally retarded observed by Senate staff was designated for 5:30 p.m. on one ward. The food for the approximately 40 residents was wheeled through the dayroom on a cart into a locked dining area. At 4:40 p.m., a carton of milk, spoon and napkin were set at each place on the tables. Ward staff said they had assembled the residents in the dayroom for no particular activity but to wait for the evening meal. Through a window, residents could see the milk on the table and food in family-style aluminum serving trays on the cart. Several residents, appearing upset, attempted to enter the dining area and were physically moved back by the staff. At 5:30 p.m., the door was unlocked and the residents were admitted to eat. Eating with the residents, Senate staff found the food to be lukewarm and the milk barely cool. The facility staff supervisor said the meal is served daily at 5:30 no matter when the food arrives. At 6 p.m., before some residents had finished their meal, direct-care staff members began washing the tables with soap and water.

"We have suggested that they try having quieter meals, close the curtains, break up the tables for three or four clients

each," said one patient advocate. "But the staff sees meals as a chore to be accomplished; something you have to do and get it over with. We could get a lot of interaction going during these meals."

Mealtime can be a particularly difficult time for direct care workers. Patients/residents must be closely observed while walking to the dining area as well as during mealtime. At one facility, rather than walk outside and risk a resident trying to escape, direct care workers escort patients through an underground maintenance area to the cafeteria. A minimum of two staff members walk with the patients, one in the front and one in the rear, to ensure that no residents try to hide in the tunnel; attack a staff member or resident; or harm themselves on the pipes exposed along the walls and ceilings.

Residents are closely watched during mealtime for potential disruptions and accidents. And accidents, at least at one hospital visited, are frequent. While Senate staff was observing lunchtime in a California hospital, a loud alarm sounded throughout the hospital grounds. Hospital staff told Senate staff that the alarm usually means someone is choking and needs assistance. The sounding of the alarm at lunchtime, hospital staff said, is not unusual.

At many of the institutions visited, Senate staff tasted the food. In the psychiatric hospitals the food was usually bland and starchy. Patients often complained of eating the same foods continually. In institutions for the mentally retarded, the food was frequently ground or pureed. On one unit, 33 of the 36

residents had their food ground. To the cook's knowledge, none of the residents were on any program to develop an ability to digest whole foods.

There is little treatment, other than medication, provided in many state institutions according to staff, patients and advocates interviewed by Senate staff.

While individual patient records may include extensive descriptions of treatment plans, Senate staff observed very little such treatment in the 31 facilities that were visited. This apparent lack of treatment was described by one facility director as "milieu therapy". When Senate staff asked for an example of milieu therapy, the director said that if it was not visible, then that was a sign it was working.

None of the other facilities Senate staff visited claimed to provide any similar invisible therapy. However, staff members and patients consistently said that therapy, other than medication, at their facility, was virtually non-existent.

At uncertified facilities, overcrowding, staff shortages, and unpredictable patient behavior are all common explanations for the lack of treatment. At many of the certified facilities Senate staff visited, hospital staff complained that they spent so much time developing and documenting treatment plans that it was practically impossible to implement them.

Most of the units Senate staff visited posted a chart of daily and weekly activities. These charts included times for meals, recreational activities, and group program and therapy

sessions. Comparing what was scheduled with what was observed, however, revealed that watching television or sleeping was actually the activity that filled a majority of a patient's/resident's day.

For some patients, getting to therapy sessions, day programming or other off-ward activity is impossible. Some psychiatric hospitals operate on a level system that grades patients' ability to handle free time. While visiting a New Jersey hospital, Senate staff was told that if a patient was not on a level that allowed him or her to leave the ward, therapy or day programming was often unavailable. Often staff either could not or would not escort patients off the ward.

At some hospitals, even the most basic social training is not provided on the ward. On an adult male ward at a Michigan hospital, one entire dormitory was reserved for bed wetters. Hospital staff said that most, if not all, of the incontinence was a behavioral problem. However, to the direct-care staff's knowledge, no treatment programs had been developed for the behavior. The incontinent men, staff said, were grouped together for convenience purposes.

In one New York facility, a male resident who is dually diagnosed as mentally retarded and mentally ill, was observed in a seclusion room naked and screaming. Senate staff was told that no formal behavior modification plan has ever been developed for this 34-year-old man who came to the facility when he was 11 years old.

While some treatment plans are never developed and others are developed but never implemented, there is one consistent treatment activity: the dispensing of medications. In psychiatric hospitals, the call to "line up for meds" can usually be heard four times a day. Varying dosages of psychotropic medications such as Haldol, Thorazine, Mellaril and others are dispensed in liquid and pill form to a majority of the patients on a ward. The percentage of residents on psychotropic medications in institutions for the mentally retarded generally is less than those in institutions for the mentally ill. However, a significant number of developmentally disabled residents are on some form of anti-seizure medication.

Many psychiatric patients have PRN's in addition to the scheduled medications. PRN's are prescriptions for additional medication to be administered on an as needed basis. Like all medications, these prescriptions must be authorized by a physician. However, Senate staff visited hospital wards where every patient had a written PRN on file in the nurses' station. These PRNs are often used to help subdue assaultive patients.

Particularly in psychiatric institutions, control appears to be the treatment goal, and medication the chief method of achieving control.

Senate staff did not request or obtain access to patient/resident medical records in any facility. For reasons of confidentiality, these records, pertaining to prescription and application of medications, are considered highly sensitive and are available only to authorized personnel. In addition, review

of these records requires the sort of individual patient assessments and sampling techniques not envisioned by this project.

Few organizations that monitor state facilities for the mentally disabled include regular, systematic monitoring of medications as part of their work, although medication practices are a major area of complaint of patient rights organizations and many patients and direct-care staff.

Medication in these state facilities is considered the principal discretionary function of physicians. The patient or advocate complaints that question the administration of medication, however, usually concern a specific drug or drugs and the dosages or side effects concerning a specific patient. Nursing staff concerns, told to Senate staff, involved such things as the "passing" of medication by untrained ward staff, the undermedication or overmedication of certain patients, the lack of adequate physician involvement, and the dangers of illegal drugs taken by some patients in combination with prescribed drugs.

Systematic review of medication procedures have revealed significant problems in New York psychiatric facilities, a state where the Commission on Quality of Care for the Mentally Disabled has substantial authority and expertise to monitor the broad spectrum of institutional issues. The Commission, in its recent review, found that "for 71 percent of the patients reviewed comprehensively documented annual physical exams were not available and that for 41 percent regular medication reviews had

not been conducted. For more than 85 percent of the sample patients, medication changes had been ordered with no documented physician rationale, a deficiency which was compounded by the often multiple treating physicians involved with the care of these patients. Standing orders for PRN medications were present for nearly one-half of the sample patients, and, significantly, only 57 percent of these orders were usually accompanied by a documented physician rationale. None of the records of the sample patients who were being treated with multiple psychotherapeutic and anticonvulsant drugs, contrary to NYS Office of Mental Health polypharmacy guidelines, contained a documented physician rationale for the use of polypharmacy. Perhaps, most shockingly, fewer than 15 percent of the sample patient records contained required documentation for the quarterly monitoring of adverse side effects from their medications are required by the Office of Mental Health." (10)

This final point concerning side effects is especially pertinent when considering the adequacy of monitoring medication practices. An estimated 20 to 40 percent of patients taking neuroleptic drugs exhibit some form of Tardive Dyskinesia (TD), an involuntary, sometimes permanent, sometimes debilitating movement disorder. Senate staff observed several patients/residents exhibiting what appeared to be involuntary movement on wards of state hospitals and facilities for the mentally retarded.

Some ward staff, including nursing staff and physicians, said the movements were a symptom of the patient/residents'

medical or developmental disorder. Three patients exhibiting the movements, when asked by Senate staff, said the movements were due to the medication and that their doctors were trying to stop the facial twitching, leg and hand shaking, or gnarling of fingers, by changing their drugs.

One recent article explored lawsuits by patients' families against physicians and warned of an "impending crisis in TD litigation."

The authors warned that "elements of clinical practice that have proven to be critical issues in the 14 cases known to us, and that may have prevented a settlement or a verdict against (the) physician, are still not routine elements of psychiatric care: these include conservative prescription of neuroleptics, informed consent, careful monitoring for early signs of dyskinesia, periodic neuroleptic withdrawals or dose reductions, documentation of positive neuroleptic effects, and skills in the diagnosis of TD.

"One is not being glib in averring that the 1980 American Psychiatric Association Tardive Dyskinesia Guidelines (American Psychiatric Association Task Force, 1979) are honored more in the breach than the keeping. In fact, a review of the history of TD demonstrates nothing as clearly as this disconcerting fact: since 1957, published guidelines, scientific articles, presentations at professional meetings, and draconian admonitions in the Physicians' Desk Reference seem to have had little, if any, effect on actual physician behavior with respect to neuroleptic drugs." (11)

Another method of control is the use of restraint and seclusion. Policies and procedures for using restraint and seclusion vary from one institution to another. The kind of restraints and seclusion used also varies.

During visits to institutions, Senate staff observed the use of leather restraints, padded restraints, camisoles and mittens. Patients/residents were observed walking on wards with their hands restrained, while others were observed with both their hands and ankles cuffed in leather restraints, or wrists and ankles restrained to a chair or bed.

In one facility, Senate staff observed a woman in 4 point restraint in a chair mounted to a wooden platform. Although the platform was in the middle of the dayroom, sheets were hung around the platform so the woman could not observe any part of the room.

In a certified institution for the mentally retarded, Senate staff observed one restraint chair bolted to the floor in the middle of a resident's room.

The most common observance of the use of restraint was restraint in beds. Senate staff observed residents who were restrained to a bed in three, four and five point restraints. (Five point restraint includes a restraint around the resident's waist). Sometimes the resident was face down. Other times the resident was on his or her back. The bed was usually, but not always, bolted to the floor in a seclusion room. In one facility, Senate staff member observed an adolescent in four

point restraint lying on his back in a bed in the middle of a crowded unit hallway.

In one facility, a patient was observed restrained to a bed naked in three-point restraint, one at each wrist and one for both legs. (At other facilities, the leg restraint would be considered inadequate, as it could allow a patient to move his legs in unison, creating a rocking motion and a possible injury to the patient). After a direct-care worker discovered the patient had urinated in the bed, the sedated patient was walked through a patient area in leg hobbles to a shower.

As a procedure that often takes place at the peak of a violent episode, restraint of patients/residents is potentially dangerous for all involved. Direct-care staff cite numerous injuries to staff from these procedures. Several facilities have "panic buttons" used to summon staff from other wards to assist in restraining patients. Staff have said that the delay in getting help makes for longer periods of physical restraint -- staff holding patients on the floor -- before sufficient staff arrives to apply mechanical restraints.

One recent investigation of the death of a psychiatric patient during a restraint procedure found no wrongdoing on the part of staff, but said, "This case does present a disconcerting reality: that eight able-bodied men, trained in managing aggressive patients, had difficulty managing one out-of-control, delusional patient."

The investigation report included data concerning restraint

and seclusion deaths in New York facilities between 1979 and 1982, which found that 19 patients in adult psychiatric centers died "during or subsequent to being secluded or restrained." Eighty-four percent of the patients were males and the average age was 32. Eighty eight percent of the deaths involved restraint only. (12)

Seclusion is often used without restraint. Assaultive patients who do not appear to intend to harm themselves are often placed in seclusion rooms without restraint. Seclusion rooms are usually empty or furnished with a mattress or bed. While seclusion rooms should always be free of debris and potentially dangerous items, Senate staff observed seclusion rooms where cups, tissues, sheets, etc., had not been removed after the room had been used. The cap of a hypodermic needle was found left on the floor in one seclusion room and, in another, a sharp piece of metal was found protruding from a window screen.

In certified institutions for the mentally retarded, the use of locked seclusion rooms is prohibited. "Time out" rooms have been designed, instead, to provide a secluded but unlocked place for a resident to be by him or herself. Some time out rooms can be locked but only with a hospital staff member pushing on a cross bar outside the room. This locking mechanism requires a staff member to be outside the room able to observe the resident through a window at all times.

Every institution Senate staff visited had written policies and procedures for the use of restraint and seclusion, as well as time out. These policies and procedures included observing the

resident at set intervals of time and documenting each of these observations in the resident's chart. At most facilities, a physician must authorize the use of restraint and/or seclusion past a certain maximum length of time for each episode. In some facilities an extended use of restraint and/or seclusion requires the approval of a facility committee.

However, although staff are required to check and document the use of restraint and seclusion in short intervals of time, Senate staff observed residents in seclusion who, hospital staff informed them, had been in seclusion for several days. In one state hospital in California, a psychiatrist told Senate staff that some patients at his hospital have been in seclusion for several months.

Senate staff was also told that suicide attempts are not uncommon while patients are in seclusion.

In a report recently approved by the American Psychiatric Association Board of Trustees, the Task Force on the Psychiatric Uses of Seclusion and Restraint states, "Seclusion serves a legitimate and irreplaceable purpose on the modern inpatient ward." (13)

Monitoring

The Advocates

During institutional visits, Senate staff encountered many different kinds of advocates and systems to protect patients' rights. On most visits Senate staff met with the institutional employee who was designated as the "clients' rights advocate." The responsibilities and design of these offices differed from state to state. Some clients' rights advocates were full time; some were part time. Some investigated allegations of abuse, while others referred all allegations of abuse to a separate investigator. Some advocates consistently visited hospital units on "rounds" to converse with patients and ask about their concerns. Some were so inundated and short staffed they often struggled to catch up with weeks-old complaints patients had forwarded to their office.

In California, the office with the responsibility for handling patients rights in each institution is authorized by state statute. This patients' rights advocate reports to a supervisor in the central office of the State Department of Mental Health.

Each California institution is also required to have a special investigator on staff who is a sworn peace officer and who is solely responsible for investigating allegations of patient abuse and client deaths. The special investigator reports to the hospital director, who, in turn, makes all final determinations of abuse and adverse action. Similarly, at state

schools and hospitals in Maryland complaints of abuse are reported to and investigated by the local police as well as by the hospital administrator and his or her staff.

While all of the institutions Senate staff visited had documented policies for reporting complaints and abuse, implementation of these policies was often impractical and ineffective.

In Texas, the Department of Mental Health and Mental Retardation has a pilot program in one state hospital for one internal patient rights advocate. The program comes complete with pages of procedure and the hospital has locked boxes into which patients may anonymously place written complaints. But the boxes are located in areas inaccessible to patients on locked wards. The alternative for these patients, the advocate told Senate staff, was to use pay telephones on the ward or tell ward staff. Both options have glaring disadvantages to complainants seeking privacy.

Michigan has boxes also, on each ward of one state hospital. Several times each week they are emptied by one of four employees of the state's Office of Recipient Rights, an advocacy agency. But in this hospital of some 1,000 patients, there are an average of 1,500 "incident" reports filed monthly and more than 200 complaints regarding abuse and other allegations of mistreatment. The office says it can investigate an average of 30 complaints a month.

In California, the patient complaint system on some wards

relies on patients telephoning the patient representative from a pay telephone located on the unit. However, each unit, of approximately 30 residents, is allotted only $5.00 worth of dimes for telephone use each month. On the average, this limits each patient to less than two telephone calls per month.

Hospital staff say patients can and do ask the staff to contact the patient representative for them. Patients, however, told Senate staff that it was awkward, intimidating and rare for a patient to ask hospital staff to contact a patient representative so that her or she may file a complaint.

In New Mexico, a state hospital housing 600 patients, has one patient advocate, a long time employee and former hospital barber. Despite a substantial body of official documentation of physical violence, revealed by a team of investigative reporters last summer, an internal state audit showed that in the first three months of 1984, the hospital's five main psychiatric wards recorded an average of "zero to one" abuse complaint per ward to the advocate. (14)

In some institutions, patients/residents can rely on outside advocates who come into the facility to visit residents and observe the level of care being provided. Many states, such as New York and New Jersey, provide protection and advocacy services to monitor institutional care in state facilities. Families and interest groups have also organized to monitor institutional care and services.

However, it is often difficult for outside monitors to

substantiate allegations of patient abuse. Access to client records is limited and credible witnesses are usually scarce.

Senate staff accompanied two state-paid investigators to one "multiple disabilities unit" of a state psychiatric hospital where two ward staff had charge of 12 young men dually diagnosed as mentally ill/mentally retarded. One patient complained he had been "beat up" by a staff member he named and said two other patients had witnessed the incident. The investigators attempted unsuccessfully to get coherent responses from the supposed witnesses. The staff member denied the incident. The investigators said they were unable to proceed further in the absence of any recent reported or observed injury.

Accompanying a lawyer-advocate to another state hospital, Senate staff observed a 16-year-old girl with a swollen index finger she said was caused by a staff member prying it back while attempting with other staff to place the girl in restraint. The girl further said she was beaten in restraints (while tied to a bed at four limbs). The lawyer later reported that the girl admitted lying about the swollen finger, but witnesses confirmed the beating in restraints. The lawyer was forced to conclude that the mixture of truth and untruth on the part of the complainant would make for a weak case and a low priority on heavy caseload.

While protection and advocacy services for the mentally retarded are expanding, such services are extremely limited for the mentally ill.

Last year, Congress amended the Developmental Disabilities Act to enhance the services and authority of state protection and advocacy agencies (P&A's) in institutions in two very specific ways. First, by no later than Oct. 1, 1986, P&A's must have access to records of institutionalized mentally retarded persons if (a) a complaint is received by the P&A and (b) the person does not have a legal guardian or the person is a guardian of the state. Second, the state must now provide copies of each annual survey of a certified facility for the mentally retarded along with the plan of corrections for deficiencies to the P&A. Both are to be received by the P&A within 30 days of completion.

Although the Developmental Disabilities Act does not specifically prohibit the state P&A's from providing services for the mentally ill, very few are served.

In a 40-state survey of services provided by P&A's, only seven percent of the total number of persons served were mentally ill.

One New Hampshire P&A attorney told Senate staff his agency's funding is inadequate to serve the mentally ill. "We can't generate business when we can't handle it," he said.

One P&A which does actively monitor and investigate state hospitals for the mentally ill is in New York. Recently the New York State Commission on Quality of Care for the Mentally Disabled conducted a review of living conditions in nine state psychiatric centers. The commission found that at the nine psychiatric hospitals there were "nine different thresholds of acceptable living conditions... What is startling is that these

different thresholds do not, at most of the centers visited, reflect variations above a minimum standard, but in several instances affect the most rudimentary aspects of the obligation of a mental hospital to care for its patients--to provide them with a clean, safe and sanitary environment; clean, fitting and seasonably appropriate clothing; nutritious and tasteful food; proper personal hygiene; and an opportunity to engage in meaningful and constructive activities." (15)

In the past, federal grant dollars have been available to develop advocacy services for the mentally ill, like those provided in New York State.

Today, there are a few self-advocacy groups receiving funds from the National Institute of Mental Health but these are relatively small grants directed toward coordinating information and advocacy services among former patients of institutions for the mentally ill.

Senate staff believe protection and advocacy services for the institutionalized mentally disabled, especially the mentally ill, are desperately needed. There are few dollars specifically available for the mentally ill and many institutionalized mentally retarded persons have not been served by the P&A's. Based on data collected from 40 states, P&A's served approximately 30,000 persons in fiscal year 1982. However it is estimated that approximately 400,000 persons (both mentally ill and mentally retarded) reside in public institutions throughout the country. Considering the P&A's provide assistance on a range of issues (i.e. education, employment, transportation,

vocational rehabilitation, medical services, housing, architectural barriers and guardianship) it is safe to assume that the vast majority of institutionalized persons do not receive services from the P&A's. Hopefully, the increased P&A appropriations approved by Congress for fiscal year 1985, as well as the new authority to serve institutionalized mentally retarded persons, will result in more institutionalized persons being served. However, until P&A services are further expanded, patients of state hospitals for the mentally ill will continue to be underserved.

Accreditation and Certification of State Hospitals for the Mentally Ill

Psychiatric facilities desiring to participate in Medicare and Medicaid must be certified by the Secretary of Health and Human Services. The first step in receiving certification is usually accreditation by the Joint Commission on Accreditation of Hospitals (JCAH), which satisfies federal requirements pertaining to physical environment, and health and safety. Currently, 348 of the 453 certified psychiatric hospitals are accredited by JCAH. In the 105 psychiatric hospitals which are not JCAH-accredited, the state agency conducts the general health and safety surveys, as well.

The second part of the process requires demonstrating that active treatment is being provided to residents of the facility. The survey to measure compliance with the active treatment standards is conducted, in 264 hospitals in 40 states, by consultants hired by the federal government with expertise in psychiatric care. In the remaining states, there are 189 certified hospitals, of which 76 are state-owned, where states used their own agencies to survey for active treatment.

The Joint Commission on Accreditation of Hospitals is a private, non-profit accrediting agency for hospitals, including psychiatric hospitals. It was chartered in 1951 as an outgrowth of the American College of Surgeons, which, from 1915-1951, conducted accreditation surveys of hospitals. JCAH activities are funded primarily from fees paid by facilities requesting

accreditation, and from its five member organizations, which include the American College of Physicians; the American College of Surgeons; the American Hospital Association; the American Medical Association; and the American Dental Association. JCAH estimates that its fiscal year 1985 budget is approximately $22 million, 70 percent of which will be derived from survey fees. It receives no federal funding.

Accreditation Process

A psychiatric facility requesting accreditation is surveyed by a team of JCAH staff over a period of several days in order to assess compliance with over 1,600 standards. The length of the survey, and the number of surveyors is based primarily on the size of the facility. A psychiatrist is always present, along with up to six other surveyors. Surveys generally last between two and five days. The cost to the facility runs about $1,245 per day per surveyor. Surveys are conducted with approximately four weeks advance notice to the facility. Facilities requesting accreditation have the option of being surveyed under either of two JCAH manuals currently acceptable for psychiatric hospitals: the Consolidated Standards Manual for Child, Adolescent, and Adult Psychiatric, Alcoholism and Drug Abuse Facilities and Facilities Serving the Mentally Retarded/ Developmentally Disabled (CSM), or the Accreditation Manual for Hospitals (AMH). A comparison of selected portions of these two manuals is contained in a subsequent section.

Standards fall into seven categories: (1) patient management; (2) monitoring activities; (3) staff qualifications;

(4) quality assurance; (5) quality and appropriateness of care; (6) therapeutic environment; and (7) environmental safety. Compliance with standards is measured by the surveyors on a scale of 1 to 5, with a 1 representing substantial compliance, and a 5 representing noncompliance.

As part of the survey, JCAH reviews 10 percent of all patient records at random to assess whether treatment plans are in place, that charting is done regularly and correctly, and whether the treatment plans are being reviewed regularly and revised when appropriate. The surveyors also tour the facility, looking at the physical plant, treatment and living areas.

In addition to a review of patient records, surveyors hold two workshops during the survey on patient management and quality assurance. These workshops are attended by staff and administrators of the hospital and focus on areas in which surveyors have found weaknesses. Surveyors explain the applicable standards more fully to the staff and make suggestions regarding possible ways to improve compliance.

At the conclusion of the survey, an exit conference is held with administrators of the facility to discuss the surveyors' preliminary findings. At this time any serious deficiencies are brought to the attention of the administration and discussed. In cases where a situation is found that threatens the public or patient safety, JCAH policy calls for state or local officials to be notified in writing. However, JCAH has never issued such a notification.

After the survey has been completed, JCAH staff go through a complicated process of scoring the facility in each major category of standards, to come up with a composite score for the facility as a whole. If substantial compliance has been demonstrated in each of these categories, a decision to accredit the facility without deficiencies will be made. If there are some areas with deficiencies, a decision to accredit with contingencies may be made. Ultimately, if there are very serious deficiencies which have either occurred over a substantial period of time or are life-threatening, a non-accreditation decision may be made.

The ultimate sanction a facility may incur is loss of accreditation. JCAH reports that two psychiatric hospitals have been de-accreditated over the last year, and estimates that about two to three percent of psychiatric facilities lose their accreditation annually.

The Senate staff review revealed problems pertaining to the accreditation process that are of concern to patients and hospital personnel in view of the JCAH role in the certification process for psychiatric hospitals.

First, accreditation surveys by JCAH are predictable. When a facility requests initial accreditation, JCAH provides the hospital with the dates of the survey approximately four weeks in advance. Also, facilities know that the surveys will occur during normal working hours; evening or night visits do not take place. Additionally, facilities may contact JCAH prior to their survey to find out the names of the surveyors.

One hospital administrator in Texas said his facility took full advantage of the advance notification of JCAH surveys. "You can always find out who is coming and where they've been and prepare for him," the administrator said. After finding out where the particular surveyor had last worked, the administrator said, administrative staff from that facility were contacted to determine what items on the JCAH checklist seemed especially important to the particular reviewer. Confusion about certain standards, the administrator added, could be settled by telephoning JCAH headquarters in Chicago for an interpretation.

The predictability of JCAH surveys was of concern to the Southern Poverty Law Center in a brief filed on behalf of the plaintiffs in the Wyatt v. Ireland case. As noted in the brief:

> "...though regulators universally recognize that it is necessary for an inspection team to conduct unannounced

visits if it is to obtain an accurate picture of how a facility functions (see Jarrell 18-19; Simmons Ex. 1 at 8, Attach. 1 at 4) J.C.A.H. notifies facilities, often months in advance, of when its survey team will be present. (Roberts 48). The commission recognizes that advance notification permits the facility to "dress up" its operations for the survey team and prevents the team from getting an accurate picture of its daily functioning. (See McAninch 256; Roberts 48)." (16)

Once accredited, hospitals must be re-surveyed every three years in order to assess continuing compliance with accreditation standards. Facilities are notified several months before their accreditation will expire, and a date is set for the survey during the 90 day period surrounding the survey anniversary date.

In cases where JCAH has accredited a psychiatric hospital contingent upon the facility's correcting specified deficiencies, the facility is notified three to four weeks in advance of the date on which a follow-up, or focused survey to measure progress towards correcting those deficiencies will occur. If, during a focused survey, the facility is still out of compliance with one or more standards, JCAH staff have several options. They may decide that a written progress report be filed by the facility, or that another focused survey be scheduled, or that the facility be de-accredited.

Approximately 50-60 percent of psychiatric hospitals are accredited with contingencies, and follow-up surveys are scheduled for three months, six months or a year after the

initial survey, depending on the severity of the problem, and the amount of time JCAH feels is required to make corrections. A facility accredited with no contingencies will likely not see any JCAH surveyors during that three-year period, and approximately 40 percent of accredited psychiatric hospitals fall into this category.

When a focused survey occurs, facilities know in advance what the surveyors will be addressing: only those standards with which noncompliance was serious enough to warrant a "C" for contingency are examined during the focused survey. Lack of compliance with a specific standard for the first time is noted in the survey report. If that same deficiency is noted 3 years hence during the next survey, the survey report will likely contain a "+" next to the standard, indicating that the facility must be in compliance with that standard by the time of the next regular survey. If, during that survey, the problem has still not been corrected, a "C" may be placed next to that standard in the survey report, denoting that this problem must be corrected by the time of the next focused survey. JCAH indicates that facilities rarely, if ever, have only one deficiency; patterns of deficiencies in a particular category of standards are common.

As evidenced by the above explanation, a facility could be out of compliance with a standard for up to six years or longer before it becomes an issue which must be addressed before re-accreditation may be jeopardized. For example, a JCAH survey of one of the hospitals Senate staff visited indicated that the standard mandating that progress notes be made regularly had been

violated on four previous surveys and was still not being met. Yet, a contingency was still not placed on the accreditation for noncompliance with this standard; a "+" was determined to be sufficient.

An additional criticism of the JCAH survey process is the limited extent to which sources outside of the hospital are contacted to obtain information about conditions inside the facility. It is true JCAH requires hospitals to post notice of an upcoming survey a month beforehand, to allow interested persons to apply to JCAH, in writing, for a public information interview during the survey. However, JCAH does not, on its own, initiate contact with state licensing officials or advocacy groups, who may well be able to provide information relevant to accreditation.

Although JCAH may initiate unannounced or unscheduled, 24 hour notice surveys of accredited hospitals, usually in response to complaints from individuals or newspaper articles, this is rarely done. In the last five years, only six such surveys have been initiated out of the approximately 530 accredited psychiatric hospitals. Before actually undertaking a survey, however, JCAH will usually share the complaints or articles with the facility and give them a chance to respond and rectify the situation. Only if JCAH has reason to believe the situation has not been corrected will it actually conduct a survey.

One former JCAH surveyor told Senate staff that such surprise-survey techniques would improve the Commission's ability to survey, but he said that, even with advance notice, hospitals

are unable to make dramatic changes that alter the survey results.

A JCAH official, in a briefing with Senate staff, said of the routine advance-notice surveys, "We've agonized over this. How do you make sure they aren't trying to blow smoke at you?"

When asked about the JCAH accreditation process, staff of JCAH-approved facilities said a substantial amount of preparation is made for the Commission's reviews. Staff uniformly said efforts are made to "spruce up" hospitals, including extra cleaning, personalization of wards, new clothing for patients and especially, improvements in paperwork.

A therapist at a New Jersey facility told Senate staff she was instructed to assemble a selected group of patients on one ward JCAH was visiting to give the appearance of a scheduled class.

A direct-care staff worker in a Connecticut hospital said that, two to three weeks before the JCAH survey, "new stuff" began showing up on his ward, including plants, pictures on the walls, and "booties" (disposable footwear) for the patients. "Everyone all of a sudden got pajamas, toothbrushes, toothpaste; suddenly they were obsessed with cleanliness. After the reviewers leave, the stuff begins to evaporate with attrition," he said.

In addition to the amenities, there is the paperwork: "Anyone who has worked in an accredited public mental hospital is familiar with the panic that precedes visits from JCAH or other

surveyors. During these panics staff concentrate on "treating the charts" and frequently neglect the treatment of patients." (17)

Direct-care staff take a cynical view of the JCAH process, noting that the ward improvements deteriorate after the commission surveyors depart as mentioned earlier. Apprised of these attitudes, facility administrators answer that the improvements are much the same as an individual would make in his own home in order to impress visitors.

An additional concern about the survey process is that facilities can hire consultants, both former and current JCAH employees or consultants, to survey the facility prior to the official JCAH survey. The current JCAH consultants who are in the business of doing these pre-surveys do provide JCAH with a list of facilities employing them within the last three years, so they will not be scheduled for an official JCAH survey of that hospital. The results of this consultation are used by the facility to determine where work needs to be done in order to have a successful survey by JCAH. While in itself this pre-survey consultation is not improper, it does suggest that facilities focus their efforts on achieving compliance just prior to their next JCAH survey, rather than maintaining compliance throughout the course of their three-year accreditation.

The JCAH proposal to require accreditation of all psychiatric hospitals under the Accreditation Manual for Hospitals (AMH) as of April 1, 1987 is troubling for a number of reasons, including the lack of standards in the AMH addressing

patients rights. A review of the AMH revealed several problems in terms of the stringency of standards. For example, the set of standards delineating patients' rights are completely omitted, and the standards pertaining to special treatment procedures have serious weaknesses. The following is a comparison of the CSM standards pertaining to patients rights and special treatment procedures.

In the CSM, there are 6 major standards governing patients rights. These standards specify the facility's responsibility to (1) inform patients of their human, constitutional and civil rights and enforce those rights; (2) protect confidentiality of patients' records and patients' personal privacy; (3) inform patients and families regarding treatment and discharge plans; (4) obtain patients' informed consent for specific treatment modalities; and (5) allow patients to work for the facility only under specific conditions. These standards are totally absent from the AMH, and in lieu thereof is a statement in the front of the manual, of patients' rights and responsibilities. Although state laws may address these rights without commensurate standards, there is no formal measure of the extent to which these rights are protected.

Supporters of the shift to AMH standards have said that the more strictly worded regulations and procedures in sections of the CSM standards are in areas of the hospital function where "direct physician involvement has been relatively less intensive or more intermittent. This is particularly true for services that involve significant risk for the patient."

In the CSM, such "highly prescriptive and detailed" procedures include those for seclusion and restraint of patients. The standards "specified details of charting appropriate indications, and the administrative review of these procedures. By contrast, the AMH mentions seclusion and restraint under the standard describing the bylaws and accountability of the medical staff. The entire reference to restraint and seclusion encompasses one paragraph...One implication of these shifts from the consolidated standards to the AMH for hospital-based psychiatric care is that psychiatry will have the same responsibility as other medical specialties to monitor its activities. It seems likely, therefore, that psychiatrists will participate increasingly, along with other physicians, in establishing and implementing quality assurance programs." (18)

Restraint and seclusion standards in the CSM mandate that the facility must (1) establish a written policy governing the use of restraint and seclusion (r/s); (2) justify clinically the need for r/s, and not allow use of r/s for punishment or convenience of staff; (3) have a physician's authorization for the use of r/s, which cannot exceed 24 hours; (4) see that staff are trained in the use of r/s; (5) not allow r/s to be used in a manner causing undue pain or discomfort; and (6) attend to the patient in r/s every 15 minutes, and allow him to bathe, use the toilet and receive meals. By comparison, the AMH standards are considerably weaker. The only requirements are that a physician must write a "time-limited" order for r/s within 12 hours <u>after</u> its initial use, and that the patients be attended to every 15

minutes as discussed in (6) above. Notably absent are restrictions limiting restraint or seclusion to 24 hours, with staff being able to place a patient in r/s and not receive authorization for it until well after the fact, and the elimination of the requirement that staff be trained in the use of r/s. The most serious omission here are the standards stating that r/s is not to be used as punishment or for the convenience of staff and that r/s are not to cause undue discomfort or pain. Again, often because no formal method of evaluating the use of restraint and seclusion exists outside of the JCAH standards, any weakening of these standards could jeopardize protection of patients' safety and health.

These categories of standards were chosen for comparative purposes because they illustrate how fundamental areas of patient care are -- and are not -- addressed by a private organization to which the federal government has transferred considerable authority to determine whether a psychiatric hospital may become eligible for federal funds.

JCAH admits that the controversy surrounding the AMH may result in alterations to the manual before it completely replaces the CSM in 1987, perhaps including a section on patients' rights. The Health Care Financing Administration accepts accreditation of psychiatric hospitals under either manual, although most hospitals have chosen accreditation under the CSM.

Several hospital administrative staff interviewed by Senate staff were critical of the scheduled shift from the CSM to the AMH manual by JCAH. The most common complaint centered on the

medical model embodied in the AMH standards, which gives the preeminent supervisory role in treating patients to the psychiatrists. It was felt that the CSM encourages a more multi-disciplinary approach to treatment that requires less costly outlays for medical staff, a significant concern for state run facilities that largely must rely on state-appropriated funds.

Several psychologists at different hospitals told Senate staff that they and the nursing staff have the actual primary responsibility for treating psychiatric patients, beyond the routine prescription and review of medications that is the psychiatrists' job. Underlying much of the criticism was a feeling that JCAH had "buckled" to pressure from medical professionals' organizations in requiring the shift. There was also strong sentiment questioning the ability of institutional psychiatrists, often foreign medical graduates, to assume broader treatment responsibilities.

A JCAH official privately acknowledged that the quality of the medical staff in public facilities is a problem in terms of their ability to provide active psychiatric treatment. However, this official also contends that the increased emphasis on competency of the staff in the AMH will force the public psychiatric hospitals to recruit and maintain a better qualified cadre of physicians, including psychiatrists.

As noted previously, JCAH has delayed requiring the shift from CSM to AMH from its original deadline. An administrator at a Colorado hospital told Senate staff the delay is evidence that

the AMH shift for psychiatric facilities "is going to die (because) it wasn't conceived logically or rationally". Many public hospitals are resisting the change to the AMH, according to JCAH, and are not making a good faith effort to improve the quality of their medical staff. Recognizing the difficulty some state hospitals may have in making the transition to the AMH, JCAH indicates it will allow them additional time to come into compliance with the new standards.

Finally, JCAH standards focus heavily on compliance with paperwork requirements. As noted in a recent article in Hospital and Community Psychiatry, "Documentation cannot be ignored, nor should it be. But there ought to be more reliance on surveyor's judgment in lieu of excessive documentation." (19) For example, compliance with the standards pertaining to treatment plans is based on whether written documentation exists that demonstrates that such a plan has been developed, that services are being provided to carry out the objectives of the plan, and notations made regarding a patient's progress toward meeting those objectives. However, those standards do not require surveyors to visit areas of the facility where therapeutic procedures are carried out to see if, in fact, the treatment specified in the plan is going on. JCAH staff indicate that during their tour of the facility, surveyors select a few active charts and sit in on treatment team meetings and therapy sessions involving those patients. However, this is not a formal procedure mandated by JCAH, but an informal check to see that treatment is in fact going on.

This reliance on written documentation can lead to a situation where psychiatric facilities, in preparation for a JCAH survey, may do "catch-up" work to bring patients' records and treatment plans up to date in order to satisfy paperwork requirements.

During the Senate staff review, such an allegation was made against one visited facility. A staff member reported that prior to a JCAH survey, documentation would be added to patients' records to indicate that certain treatment procedures, such as psychotherapy, were taking place, when in fact they were not. This staff person also alleged that charts which had not been kept up to date or were not "presentable" would be hidden in order to avoid inspection by the surveyors. Senate staff heard from sources familiar with this facility that very little, if anything, in the way of treatment is provided to patients, aside from medication.

A former employee of one hospital told Senate staff that JCAH surveyors reminded the staff that patients' records should never be altered. This would indicate that the surveyors noticed that changes had been made in some records, but decided not to confront the issue directly. In this particular case, JCAH made a decision to re-accredit the hospital. Contingencies were placed on that accreditation, but were not related to treatment plan or patient record requirements.

There is a widespread impression that JCAH reviews only the bureaucratic functions of a hospital. A Texas administrator said that, because of JCAH, "We do a much better job of writing than

we ever did and to a lesser degree, a better job of programming."

A direct-care worker in the same facility said, "I don't think they sample what's important. They want us to do well. (Their review) has no connection to patient care."

A programming specialist (teacher) at a New Jersey hospital told Senate staff: "what JCAH looks at mostly is the paperwork and the charts. From my experience, they examine the program very little. They really are much more interested in seeing what's on paper, seeing what programs are on paper and treatment plans completed and up to standard, progress notes completed..."

The concern that JCAH surveys focus too heavily on paperwork is shared by the Southern Poverty Law Center in the Wyatt v. Ireland brief mentioned earlier. The brief states:

> "...in practice, the survey team must rely primarily on what is contained in hospital records and on what they are told by hospital administrators...Because the survey process does not assure that the information obtained from these sources will accurately portray the internal functioning of the facility, (see Jarrell 32; Warner 64-65) the conclusions of the survey team concerning the facility and whether it promotes the provision of quality care cannot be relied upon...As a result of the peculiar focus of the Commission's survey process, the Commission's investigations are not designed to assess whether the treatment planned and provided by a facility is adequate or meets patients needs, (see Simmons 12,63; Warner 29,55) by far

the greatest flaw in the Commission's survey process." (20)

This sentiment is echoed by direct-care staff who further report that JCAH surveys do not examine what the staff feels is the most important task of the hospital: care of patients. Many staff said they welcome independent reviews of patient care, noting the occasional administrative shakeups, reviews by state legislative groups, and press investigations resulting in increased attention on, and improvements to patient care.

In sum, reliance on accreditation by the JCAH as a determinant in Medicare/Medicaid eligibility may not be appropriate because the standards set forth in federal statutes cannot be assumed to be met simply because a psychiatric facility is accredited.

Certification Process for Psychiatric Hospitals

An additional opportunity for the federal government to monitor conditions in psychiatric hospitals exists when those facilities desire to participate in the Medicare and Medicaid programs. Psychiatric facilities must be certified by the Secretary of Health and Human Services in order to receive federal funds through the Medicare and Medicaid programs, established by Titles XVIII and XIX of the Social Security Act, respectively. This certification is granted to facilities that first demonstrate they meet both health and safety standards established for all general hospitals, as well as two special conditions applicable specifically to psychiatric hospitals.

Coverage

Medicare covers individuals aged 65 and over for a lifetime benefit of up to 190 days for inpatient psychiatric care. Individuals under the age of 65 may be also covered if they have been receiving Social Security benefits for 2 years as a result of disability, with the same 190-day lifetime benefit restriction.

Medicaid coverage of inpatient psychiatric care is an optional benefit which is currently offered by 40 states for individuals age 65 or older, and in 33 states for those under 22. Individual eligibility for Medicaid inpatient psychiatric care extends only to those individuals under the age of 22 and 65 years or older. In other words, the adult population from 22 to 65 are not covered for these services, even if they would be

eligible for Medicaid if not hospitalized.

The Health Care Financing Administration (HCFA) estimates that in fiscal year 1983, federal Medicaid expenditures totaled approximately $615 million and Medicare expenditures were roughly $200 million for inpatient psychiatric care rendered in psychiatric facilities. These amounts exclude reimbursement for psychiatric care provided in general hospitals, for which data is not available. HHS estimates that reimbursement to general hospitals for inpatient psychiatric care may increase total Medicare and Medicaid expenditures by several hundred million dollars.

Certification

As mentioned above, the first step in becoming a certified psychiatric hospital requires that a hospital meet federal health and safety standards applicable to all general hospitals. Until July, 1984, the Social Security Act mandated that this requirement had to be satisfied through accreditation by the JCAH. However, Medicare regulations allow part of a hospital to participate in Medicare in cases where the entire hospital is not JCAH-accredited. Through this provision, the state, usually the health department, surveys the hospital. If the "distinct part" of the hospital meets the federal requirements for psychiatric hospitals, the state agency would recommend certification to the Health Care Financing Administration (HCFA) regional office. The regional office, assuming there were no other problems, would then certify the facility as a "distinct part". The philosophy

behind this provision is to allow a hospital which could not meet JCAH standards in their entirety to focus its resources, particularly staff, in a smaller area, thus, bringing this area (perhaps a wing, or even one or more buildings of a multi-building facility) into compliance with federal standards. Therefore, non JCAH-accredited psychiatric hospitals can be eligible for federal money. Of the 430 psychiatric hospitals currently participating in Medicare and/or Medicaid, 345 are accredited by JCAH.

The Deficit Reduction Act of 1984 (DEFRA), included a provision repealing the Social Security Act requirement that psychiatric hospitals must be accredited by JCAH in order to participate in Medicare and Medicaid. JCAH had sought this amendment for years because of its belief that legislatively mandating accreditation for the purposes of Medicare and Medicaid eligibility largely removes the voluntary nature of the accreditation process. JCAH staff stated their view that psychiatric hospitals do a better job of meeting standards when they do so of their own volition.

This change in the law does, however, allow a non-accredited psychiatric facility desiring to participate in Medicare and Medicaid to apply to the state agency for a survey to determine compliance with federal standards. Prior to DEFRA, state agencies could only conduct surveys of "distinct parts" of non-accredited facilities. In addition, DEFRA gave the Secretary of Health and Human Services the authority to rely on other, unspecified accrediting agencies to determine compliance with

Medicare requirements. Nevertheless, HCFA indicates it has no plans to recommend using any other agencies for this purpose.

Special Conditions Pertaining to Active Treatment

After demonstrating compliance with federal health and safety standards, either by virtue of accreditation by JCAH or a successful state agency survey, psychiatric hospitals must also show that active treatment is being provided to patients of the hospital. The provision of active treatment is mandated by the Social Security Act. However, nowhere in the Social Security Act or in the conditions of participation set forth in the regulations is the term "active treatment" actually defined. Even though it is not defined, it is to be measured by compliance with two special conditions pertaining to the adequacy of medical records and qualified staff, which are discussed below.

The first special condition states that the medical records maintained by a psychiatric hospital must be sufficient to determine "the degree and intensity of the treatment provided" to residents of the facility. (42 CFR, Chapter IV, Subchapter B, Sec. 405.1037). The 12 components of this requirement all necessitate that an examination of patients' medical records be made for documentation of psychiatric history and diagnosis, treatment plans and procedures, and progress notes.

The other special condition mandates that sufficient numbers of qualified staff are employed by the facility to implement plans of active treatment for residents of the facility. In some cases, the types of qualifications for certain staff are

specified, but not uniformly. In determining the numbers of staff, "adequate" and "sufficient" are the guidelines to be followed. No ratios of staff to patients are set forth, leaving the surveying agency to decide if enough staff are present to carry out treatment plans.

The regulations do not specify what "active treatment" consists of, but state that the physician must certify that "services were required for either: (1) treatment which could reasonably be expected to improve the patient's conditions; or (2) diagnostic study". (42 CFR, Chapter IV, Subpart P, Sec. 405.1629 (a)). Additionally, the training manual for NIMH consultants states that the objectives are:

> "1. To assist the patient to attain or restore to optimal psychological, psychological, physical and/or social function of which he/she is capable.
>
> 2. To improve the patients' condition to the extent that eventually such services requiring hospitalization will no longer be necessary." (21)

Neither of these objectives indicate what treatment is to consist of nor how to achieve it.

Under Medicare the states are responsible for surveying psychiatric facilities to assess whether they comply with all the applicable conditions of participation. However, in the case of the two special conditions, states experienced substantial difficulty in recruiting and maintaining the cadre of qualified psychiatrists, psychiatric nurses and psychiatric social workers

needed to assess compliance. Additionally, there was a concern that a conflict of interest might arise when a state agency was responsible for recommending certification of its own psychiatric facilities.

As a result, in 1969, an agreement was entered into between the Health Care Financing Administration (HCFA), which administers the Medicare and Medicaid programs, and the National Institute of Mental Health (NIMH) whereby NIMH would recruit such professionals as consultants to be available to states upon request to conduct these surveys. From 1969 until January 1, 1985, states were able to request NIMH assistance in conducting these surveys. NIMH data indicate 40 states used NIMH consultants for this purpose, while six conducted their own surveys, and four have no participating psychiatric hospitals. However, the six states with certified psychiatric hospitals that do not use the NIMH consultants contain nearly half the nation's mentally ill population residing in state psychiatric hospitals. These states are New York, New Jersey, Georgia, Minnesota, Illinois, and Wisconsin. HCFA indicates that 253 of the approximately 432 certified psychiatric hospitals were surveyed by NIMH consultants in FY 1984.

The 80-90 consultants hired by NIMH to conduct these surveys have been professionals in the fields of psychiatry, psychiatric nursing, psychology, social work, pharmacy, and activity therapy. All were currently working in their fields, and did surveys for NIMH several days a month.

But, beginning in January 1985, this interagency agreement

was terminated. The reason cited by HCFA and NIMH for the termination was that the four full-time personnel positions needed to administer the program at NIMH were no longer able to be absorbed within the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) personnel ceiling. Over the last few years, ADAMHA has undergone substantial staffing reductions, with NIMH suffering the preponderance of reductions. Under an HHS rule, heretofore unenforced in this case, an agency requesting services from another agency must provide the personnel to carry out the requested service, and HCFA was unable to provide NIMH with the four personnel positions, again because of staff reductions. The first quarter of fiscal year 1985 was a transition period during which NIMH continued to run the program, after notifying HCFA that it would not be able to administer the program after Jan.1, 1985.

HCFA has now taken over the administration of the surveys for the two special conditions. HCFA indicates that it will continue to use the same consultants employed by NIMH, but that it will contract out for the administrative management of the survey program. HCFA has issued a request for contract (RFC) for this purpose, stipulating that NIMH consultants continue to be used.

Several of the NIMH consultants have expressed concern that NIMH will no longer be administering the program. Because of the credibility of NIMH in the mental health community, and the responsiveness of NIMH staff in providing technical assistance to surveyors, some consultants are fearful that the lack of HCFA

staff expertise in this area will jeopardize the integrity of the survey process. The concern was also raised that an agency, such as a management firm, would seek to minimize costs, maximize profits, and thus encourage less rigorous surveys. Nonetheless, HCFA asserts that it has added the necessary expertise to its staff with two psychiatric nurses, and will closely monitor whatever contract is implemented to ensure the quality of the surveys. HCFA further indicates that the former NIMH consultants have unanimously agreed to continue to conduct the surveys for HCFA. Neither HCFA nor NIMH are pleased that the interagency agreement was terminated.

Several issues are of concern in the certification and monitoring processes for psychiatric hospitals participating in the Medicare and Medicaid programs. One of the underlying problems is the vagueness of the Social Security Act provisions determining the criteria for participation by psychiatric hospitals. The legislation, while mandating that "active treatment" be provided, is silent as to what constitutes "active treatment". The same is true of the regulations stating the conditions of participation for psychiatric hospitals. With no legislative or regulatory statement of the methods by which to accomplish active treatment or the goals of such treatment, assessments of whether sufficient qualified staff and adequate medical records exist to carry out active treatment become a subjective decision.

Second, while statutory authority exists for HCFA, through appropriate state agencies, to conduct surveys of psychiatric hospitals to ascertain whether they are meeting statutory conditions of participation, this authority is underutilized. The Social Security Act gives the Secretary of Health and Human Services the authority to enter into agreements with states whereby appropriate state agencies may conduct validation surveys of JCAH-accredited facilities. Hospitals are chosen for these validation surveys either on a selective-sample basis, or on the basis "of substantial allegations of the existence of a significant deficiency or deficiencies which would, if found to be present, adversely affect health and safety of patients." (Social Security Act, Section 1864 (c)). The regulations implementing this section state that a "substantial allegation

means a complaint which reflects on the health and safety of patients and raises doubts as to a hospital's compliance with the conditions of participation." (CFR 42, Chapter IV, Section 405, Subpart S, Section 405.1901) Therefore, HCFA may initiate surveys, for example, in response to complaints of abuse, which clearly affect the patients' health and safety.

However, HCFA has not aggressively used this tool to ascertain compliance, and estimates that, at best, only five percent of psychiatric facilities receive validation surveys on an annual basis. In fiscal year 1983, HCFA stated that only 12 validation surveys were conducted of the 348 JCAH-accredited hospitals participating in Medicare and Medicaid. HCFA may also send its own staff to survey a facility, usually based on complaints regarding quality of care. While information provided by facilities visited during the course of Senate staff's review indicate that every one has taken disciplinary action against staff for confirmed cases of abuse of patients, HCFA was unable to provide Senate staff with the number of unannounced visits it conducted over the last year in response to complaints.

A third area of concern pertains to the time frames established for correction of deficiencies found during a state certification or validation survey. The regulations provide that facilities found to have deficiencies must submit a plan for correcting those deficiencies "within a reasonable amount of time acceptable to the Secretary." (42 CFR, Chapter IV, Subpart S, Section 405.1907) The regulations further provide that the state survey agencies must monitor facilities to ensure that

corrections are, in fact, made during that period of time. However, this monitoring may or may not include on-site visits to measure progress; written reports frequently suffice.

These time frames are to be determined after taking into account "the nature of the deficiency, and the state survey agency's judgment as to the capabilities of the facility to provide adequate and safe care". (42 CFR, Chapter IV, Subpart S, Section 405.1907 (b)). Although 60 days is the regulatory guideline for correcting deficiencies, the state agency may recommend additional time if it is not "reasonable to expect compliance within 60 days" (42 CFR, Chapter IV, Subpart S, Section 405.1907 (b)).

With no federally-mandated time frames for correction, a facility which is able to demonstrate progress toward correcting deficiencies is rarely, if ever, decertified, even if agreed-upon deadlines are not met. Certified psychiatric facilities can be terminated from Medicare and/or Medicaid in the case of "immediate jeopardy", which HCFA indicates has never been done.

Additionally, there is a potential for a conflict of interest when it is the states themselves, through their survey agencies, which must certify to the federal government that facilities within their borders meet the Medicare and Medicaid requirements. In the case of a state hospital, the financial consequences of decertification are great: whatever federal funds are lost as a result of termination from Medicare and Medicaid must be made up, to the extent possible, with state funds. Therefore, there are substantial disincentives for a state to

decertify a state-run facility, and all the more reason to give a hospital with deficiencies as much time as possible to come into compliance. The following situation, which came to the attention of Senate staff during the course of the investigation, dramatizes this potential conflict of interest.

During the 1984 Medicaid state survey of a state-run psychiatric hospital, the survey team reported that "nursing services have deteriorated to such a degree that care does not meet minimally acceptable standards." (emphasis not added) This language was a replacement by a state official of a description by the survey team, which had determined and written that nursing services were "negligent". The language was virtually identical to language contained in the team's 1983 report, which concluded with the statement that "...significant improvement in the areas of nursing and social services should be undertaken immediately...".

Yet, in 1984, the level of nursing care was still found to be extremely poor. The hospital was told to submit a plan of correction addressing these and other deficiencies within 30 days. The nurse on the survey team expressed frustration that no attempts to investigate or de-certify the facility had been undertaken, even after two years of documented serious deficiencies. Even though facilities can be terminated from Medicare and Medicaid participation if deficiencies jeopardize the health and safety of patients, a decision was made at the state level that the quality of nursing care had not, in fact, deteriorated to that level. Even though the HCFA regional office

receives copies of these survey reports, no survey has been initiated as a result of these negative reports.

Fifth, no minimally acceptable levels of care are specifically mandated under the Social Security Act or the implementing regulations. The regulations do permit exclusion or termination from the Medicare and Medicaid programs or a disallowance of federal Medicaid payments previously made when the services of a participating psychiatric hospital are "of a quality that does not meet professionally recognized standards of health care". (42 CFR, Chapter IV, Subpart B, Section 420.101 (2)). The determination that a facility is providing substandard care is made on the basis of documentation provided by several sources, including state licensing or certification authorities, peer review organizations, professional societies, and "other sources deemed appropriate by HCFA". (42 CFR, Chapter IV, Subpart B, Section 420.101(b)).

Again, the decision to terminate a facility from participation becomes a subjective one, due to the lack of mandated minimal levels of compliance. Additionally, the survey reports of JCAH are not regularly provided to the Secretary of Health and Human Services. In fact, the Social Security Act protects the confidentiality of the surveys, and requires only that the survey reports be released to the Secretary, or the state agency as her designee when requested. Therefore, the situation often arises that HHS may not even be aware of deficiencies in JCAH-accredited facilities unless it receives a complaint that subsequently prompts a survey.

Finally, the question arises as to how diligently the states, to which the federal government has entrusted much of its power to conduct certification and monitoring, actually carry out these responsiblities. The state survey agencies play extremely powerful roles in determining whether psychiatric hospitals may participate in Medicare and Medicaid. While these agencies have the leverage of severe sanctions, including decertification, these tools are not aggressively used. Hospitals need only demonstrate that they are trying to come into compliance to be granted frequent extensions of deadlines. Unless the federal government assumes a more active role in assuring that health and safety standards are met, and that the intent of the legislative mandate for active treatment is fully implemented, the quality of life for patients in many psychiatric hospitals will continue to be, at best, substandard.

Certification of Institutions for the Mentally Retarded

Medicaid is the major federal source of funds for residential and related services for mentally retarded and other developmentally disabled persons.

Under the federal Medicaid law (Section 1905(c) of the Social Security Act), an intermediate care facility is an institution which: (1) is licensed under state law to provide, on a regular basis, health-related care and services to individuals who do not require the degree of care and treatment which a hospital or skilled nursing facility is designed to provide, but who, because of their mental or physical condition require care and services (above the level of room and board) which can be made available to them only through institutional facilities; (2) meets standards prescribed by the Secretary of Health and Human Services as he or she finds appropriate for the proper provision of this care; (3) meets standards of safety and sanitation which are established by the Secretary in regulation in addition to those applicable to nursing homes under state law; and (4) meets requirements for protection of patients' personal funds.

In 1971 the Medicaid statute was amended to allow for federal reimbursement to institutions serving mentally retarded and other developmentally disabled persons. The statute specifies (section 1905(d)) that intermediate care facility services may include services in a public institution (or distinct part thereof) for the mentally retarded or persons with related conditions if among other things: (1) the primary purpose

of the institution (or distinct part thereof) is to provide health or rehabilitative services for mentally retarded individuals and the institution meets such standards as may be prescribed by the Secretary; and (2) the mentally retarded individual is receiving active treatment. These facilities are called intermediate care facilities for the mentally retarded and persons with related conditions (ICFs/MR).

The regulations at 42 C.F.R. 435.1009 define "persons with related conditions" to mean individuals who have epilepsy, cerebral palsy or other develcpmental disabilities as defined under the Developmental Disabilities Services and Facilities Construction Act, P.L. 91-517, as amended.

Since Medicaid is primarily a state program, the responsibility for annually surveying and certifying ICFs/MR lies with a state designated agency. The state agency may not enter into a provider agreement with a facility unless it has certified that specific standards are met. The certification process involves an on-site visit by the state certifying agency, responsible for assessing the facilities' compliance with 693 survey items representing 116 standards. If a standard is not met it is considered a deficiency and the facility must submit a plan of correction to the state. The state is responsible for monitoring the plan of correction for each deficiency. If the corrections are not made the state can continue to certify the facility if it is determined that a good faith effort was made towards meeting the plan.

States are authorized to terminate a facility from the

Medicaid program if the deficiencies jeopardize the resident's health and safety or seriously limit the facility's ability to give adequate care.

However, from 1981 to May 1984, no state terminated the Medicaid eligibility of an ICF/MR facility with 15 beds or more.

The authority of the state to certify its facilities for federal reimbursement creates a possible conflict of interest since the state must determine whether or not its facilities are eligible for those funds. If it determines that they are not eligible, then in all probability the state itself would have to make up the loss of federal funds with state funds.

In a brief filed on behalf of the plaintiff in Wyatt v. Ireland, the Southern Poverty Law Center addresses the issue of state agencies surveying state institutions and quotes two experts on certification/accreditation.

"As Dr. Steven Taylor, a Syracuse University professor who has extensively studied the Medicaid survey process, notes:

> 'I consider that an inherent conflict of interest (exists) with one state agency monitoring another state agency given the large amount of Medicaid dollars at stake and given the fact that in many states these Medicaid dollars are important to services. I think ...there may be a built in tendency for the monitoring not to be as rigorous as it might be were a totally independent body involved in the monitoring. That's an inherent weakness in the surveying process.'

"Kenneth Crosby, the Director of the Accreditation Council for Services for Mentally Retarded and other Developmentally Disabled persons (ACMRDD), a national accreditation agency for facilities for the mentally retarded, has been told by state ICF/MR surveyors that deficiencies identified by on-site surveys are sometimes removed at an administrative level following submission of their reports. In Dr. Crosby's own words,

> '...It was made very clear that certain state survey agencies at least did not want their surveyors to make accurate and reliable assessments of compliance with the Medicaid Standards, because had they done so it might have resulted in loss of federal funds by state operated facilities.'

(Crosby 19-20; see Hubbard 21; Cook; Klebanoff 42-43)." (22)

Federal Monitors

A check on this potential conflict of interest is the Federal "look-behind" authority. In 1980, P.L. 96-499 authorized the Secretary of Health and Human Services (HHS) to conduct surveys to make an independent determination of a facility's compliance with requirements. The Secretary of Health and Human Services is authorized to terminate a facility's participation in Medicaid if there is immediate jeopardy to the health and safety of the residents or if the deficiencies seriously limit the facility's capacity to give adequate care.

Senate staff, however, has found that the Department of

Health and Human Services "look behind" activity has been limited and does not ensure timely corrections of policy or practice when deficiencies are identified. In 1984, look behind surveys were conducted in only 5 percent of the 2,200 ICFs/MR. To enhance the ability of HHS to send more surveyors into ICFs/MR to review state certification findings and to increase the presence of federal monitors, Congress, at the initiative of Senator Weicker, included the funds for 45 new look behind surveyors in the Fiscal Year 1985 HHS appropriations bill (P.L. 98-619). The Health Care Financing Administration estimates that with the additional 45 surveyors it could conduct look behind surveys annually for 100 percent of facilities with 300 or more beds; for 40 percent of facilities with 16-299 beds and for 20 percent of facilities with 15 beds or less. As of Feb. 14, 1985, HHS indicated that 36 of these positions had been filled.

In a July 31, 1984 hearing held by the Senate Subcommittee on the Handicapped and the Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Secretary Heckler presented the results of 17 look behind surveys HHS had recently conducted. Secretary Heckler stated:

> "All of the 17 facilities inspected were substandard. Nine had major health and safety deficiencies... In all cases where substandard conditions were noted during the recent Federal inspections, State medicaid directors have been given 30 days to respond with a firm, detailed plan for correcting these deficiencies within 180 days. Failure to deliver an acceptable plan or inadequate

implementation of that plan will result in termination of the facilities from the Medicaid Program."

Aug. 31, 1984 marked the deadline for receipt of these plans. In a Dec. 19, 1984 letter to Senator Weicker, Secretary Heckler stated that HHS had approved plans for seven of the nine facilities that had major deficiencies and the HCFA Regional Offices had approved five plans of correction. Five plans were outstanding at that time. Four months after the stated deadline, HHS had still not approved five plans of correction for institutions in which federal monitors had noted substandard conditions. In a March 4, 1985 letter, six months after the deadline, Secretary Heckler stated that plans of correction had been approved for 16 of 17 facilities.

Even when an institution submits a plan of correction there is no guarantee that actual corrections will be made. Repeatedly, an institution can re-submit plans of correction if deadlines are missed or plans do not initially receive HHS approval.

In the 1982 brief filed on behalf of the plaintiffs in Wyatt v. Ireland, the Southern Poverty Law Center included an analysis done by Dr. Steven Taylor of the Medicaid records at Mansfield Training School in Connecticut from 1978-1981. This analysis provides a graphic example of how long deficiencies may continue before being corrected.

"In 1978, the average number of deficiencies found at the seven different units at Mansfield was 69. By 1981,

there were an average of 151. The facility's compliance with the Medicaid Standards actually decreased over time! (Taylor 32).

"As already noted, where deficiencies exist, Medicaid requires the preparation of plans of correction, which are designed to bring facilities into compliance with the Medicaid standards. Yet at Mansfield, the percentage of deficiencies corrected actually decreased over time from 55 percent in 1978 to 16 percent in 1981, 'indicating that the facility was less able in 1981 to correct deficiencies than it was in earlier years.' (Taylor 33). Further, the deficiencies noted for correction often appear year after year in survey reports even though they have been repeated as corrected in the course of the previous survey year. (Taylor 25-29)... Dr. Taylor's report found a telling example:

> 'In one deficiency report we reviewed, we found that the deficiency stated that residents were lying in their own feces and urine during the day. The plan of correction was simply to state that our nursing policy will be revised to state that residents shall no longer lay in feces and urine.'

Plainly, the Medicaid process tends to minimize the importance of planning and permits acceptance of the most meager types of statements as so called "plans of correction". Equally plainly, serious deficiencies cannot be rectified without detailed planning."

The brief continues to explain:

> "The deficiencies also go uncorrected because, even where deficiencies are found, the criteria for deciding not to grant or to continue decertification are so ambiguous as to give ready play to the impulse to certify that affects both state and federal levels of the Medicaid system. The initial certification decision depends on the state survey agency's acceptance of the agency's plan of correction, but, the determination of whether or not a plan of correction is acceptable is left simply to 'professional judgment'. (Green 166-68). Should the federal government conclude that a state certified institution in fact does not satisfy the requirements for participation in the Medicaid program, it too retains discretion not to proceed to terminate the institution, and it too makes its decision without guidelines that provide criteria for deciding that particular deficiencies require termination while others do not. (Boone 148-49)." (23)

HHS can withhold payments to facilities for a period of time for certain deficiencies. Although HHS has withheld payments, it has only terminated one facility from the Medicaid program. Bellefontaine Habilitation Center in St. Louis, Mo. was terminated from the program in April 1984 for deficiencies of immediate jeopardy to the health and safety of the residents. This facility was later recertified when corrections were made.

Like the HHS look behind survey, state surveys focus more on

written policies and plans than actual practice and treatment.

Survey standards outline requirements for administrative policies and procedures, personnel policies, resident living standards, staffing, safety, sanitation and others. One critical component of these standards is the concept of active treatment. The current regulations address active treatment in the following manner:

> Active treatment in institutions for the mentally retarded requires the following:
>
> (a) The individual's regular participation, in accordance with an individual plan of care, in professionally developed and supervised activities, experiences, or therapies.
>
> (b) An individual written plan of care that sets forth measurable goals or objectives stated in terms of desirable behavior and that prescribes an integrated program of activities, experiences or therapies necessary for the individual to reach those goals or objectives. The overall purpose of the plan is to help the individual function at the greatest physical, intellectual, social, or vocational level he can presently or potentially achieve.

The survey instrument contains measures of active treatment, such as the requirement that a training and habilitation plan be

developed for each resident and staffing ratios for direct care workers.

However, the majority of certified institutions surveyed by the Department of Health and Human Services prior to the July 31, 1984 hearing, discussed previously, were cited for their failure to provide active treatment. For example, a February 13-24, 1984 look-behind survey at Mansfield Training School in Connecticut found the active treatment rate to be 44 percent. This was considered to be "unacceptably low." A July 25, July 28, and Aug. 10, 1984 survey of Mansfield Training School noted the following:

> "On day one of the survey, three residents were observed in the residence throughout the morning with no active staff/client interaction of any kind. One resident was observed repeatedly engaging in potentially self-dangerous behavior for a two hour period without staff intervention. The one staff member on duty in the residence was engaged in clerical and housekeeping duties."

Other recent surveys stated:

> "Many clients were observed in meaningless tasks and inactivity in living units." (From a February, 1984 survey of Bellefontaine Habilitation Center, St. Louis, Missouri.)

> "Quality, quantity and intensity of treatment programming provided to clients has been reduced to an unacceptable

degree." (From August, 1984 survey of Letchworth Village Developmental Center, Thiells, N.Y.)

"On one of the units, a client was lying on the floor directly adjacent to a radiator. When questioned the staff member responded that the client usually did this because he liked the warmth. This indicated evidence to us for client reprogramming and staff reeducation training." (From an August, 1984 survey of J. N. Adam Developmental Center, N.Y.)

"The seven clients were either sitting listlessly in chairs or pacing aimlessly around the room." (From an April, 1984 survey of Newark Developmental Center, Newark, N.Y.)

"Of 47 records reviewed, only 9 were receiving active treatment... Because of the lack of program plans for many residents, the residents were observed to be spending several hours in their cottage placements in unstructured activities." (From a February, 1984 survey of Pauls Valley State School, Pauls Valley, Oklahoma.)

All of the ICF/MR standards are 10 years old and in need of updating. HCFA has held a series of meetings and received input from over 21 groups and agencies concerned with revising the regulations. In particular, Secretary Heckler told Senator Weicker in April 1984 that much effort has gone into refining the active treatment standards so they will be enforceable and result in appropriate treatment of residents. The issuance of new

regulations, the Secretary said, would be at the top of her agenda. As of the spring of 1985, however, Secretary Heckler was still unable to predict when a notice of proposed rule making would be issued.

It is interesting to note that, despite the attention being focused on the need to improve active treatment, the Office of the Inspector General (OIG) of HHS has recently begun a series of audits intended to recover funds spent in ICFs/MR for training. The OIG has completed audits in seven states and recommended withholding a total of approximately $34 million in federal Medicaid funds. According to the OIG, the federal government could save about $585 million over the next five years if the recovery of funds continues.

The Inspector General contends that Medicaid coverage for education and vocational training is precluded, and that only habilitation services are eligible for reimbursement. However, the ICF/MR regulations require that services be provided which "help the individual function at the greatest physical, intellectual, social or vocational level he can presently or potentially achieve."

In Iowa, HCFA has been reimbursing the state for rehabilitation services which HHS now classifies as educational. These services are reported to include sign, color and name recognition.

A February 1985 survey of state mental retardation officials reported that 16 of 22 states reporting audit

exceptions/disallowances by OIG had Medicaid payments for educational services as at least one of the grounds for those disallowances. One state mental retardation official summarized the situation as follows:

> "When a state furnished ICF/MR residents with 'active treatment services,' as required by federal law, we are being told such expenditures will be treated as non-allowable costs. On the other hand, should the state fail to provide such services, our ICF/MR facilities will be decertified for failure to comply with the statute and minimum federal standards. Talk about a "Catch-22!"

While ICF/MR standards require a certified facility to have written policies and procedures insuring the civil rights of all residents, numerous violations of these rights have been documented during certification surveys. Citations include:

> "The human rights of clients were not safeguarded and their dignity was not fostered as evidenced by the number of clients observed nude in buildings...Female clients were completely exposed to staff and visitors both male and female...A male client was in the dining room in his underwear, seated at a table. He was fully exposed and was masturbating while eating. Female clients were in close proximity at the next table. There was no attempt by staff to address the situation." (From a July, 1984 survey of Staten Island Developmental Center, Staten Island, N.Y.)

"One resident was observed to be restrained naked and lying on a bed without any sheets." (From a March, 1984 survey of Belle Chasse State School, Plaquemine, La.)

"I saw a young man asleep on the floor in the toilet stall with his pants around his ankles. I was advised that (the resident) does this all the time." (From an August, 1984 survey of J. N. Adam Developmental Center, Perrysburg, N.Y.)

"There was no evidence that a Resident's Bill of Rights existed." (From a April, 1984 survey of Newark Developmental Center in Newark, N.Y.)

"Each resident is not free from physical abuse as evidenced by numerous injuries..." (From a August, 1984 survey of Southwestern Developmental Center, Bainbridge, Ga.)

"A review of the accident and incident log noted numerous instances of clients sustaining abrasions, lacerations, discolored bruises, and ecchymatic breakdown." (From a August, 1984 survey of Letchworth Village Developmental Center, Thiells, N.Y.)

"A review of the clinical autopsy of three deaths for the months of February, 1984 and an analysis of two of those records raises questions about patient management." (From a March, 1984 survey of Belle Chasse State School in Plaquemine, La.)

"Lack of specialized programs for prevention of sudden, unexpected deaths ex: There were 61 deaths in 1983, 4 of 7 died from choking; there were 10 deaths in the first 1/4 of calendar year 1984." (From a August, 1984 survey of Letchworth Village Developmental Center, Thiells, N.Y.)

ICF/MR Medicaid dollars are spent in large institutions for the mentally retarded and there is little federal financial incentive for states to create smaller alternative settings.

ICF/MR facilities range in size from 4 to 2,000 beds. Over 90 percent of mentally retarded persons in ICFs/MR reside in facilities with 16 beds or more. Facilities with under 200 beds are often administered by the private sector, while those with 200 beds or more are usually public institutions. In 1982, 91,084 beds (or 66 percent) of the total number of ICF/MR certified beds were in institutions of 301 or more persons. Despite the fact that ICF/MR funds can be used for small residential settings, they are predominantly going to larger institutional settings. While the proportion of ICF/MR beds in institutions of 301 or more beds has decreased (from 81 percent in 1977 to 66 percent in 1982); the actual number of beds in ICFs/MR of 301 beds or more has increased (from 78,256 in 1977 to 91,084 in 1982).

In 1982 small residences of 15 beds or less represented only 7 percent of the total number of ICF/MR beds. By contrast, mentally retarded persons in small group residences throughout the country represented 21 percent of the total number of

mentally retarded persons living in any sort of residential facility.

A study conducted by the National Association of State Mental Retardation Directors found that between 1977 and 1980 states spent $933 million for construction and renovation of mental retardation facilities. Eighty-three percent of that money was spent primarily to upgrade facilities so they would meet standards for ICFs/MR and qualify for Medicaid funds. Thus, states are in a position of having spent significant state dollars to upgrade institutional facilities. Naturally, they have a stake in keeping those institutions operational in order to capitalize on that investment, often at the expense of developing community alternatives.

Furthermore, many states are now in a position of facing increased expenditures if a resident of an institution is transferred to a small residential setting. In order to be certified for Medicaid reimbursement, an initial capital investment for renovations of a community residence is often required. If a community setting is not certified as an ICF/MR, the state would lose the federal Medicaid contribution. Thus, the transition from an institutional based delivery system to a community based living system represents a second set of initial capital investments.

Responding to questions from Senator Weicker, Secretary Heckler stated that "if a client is eligible for the ICF/MR level of care, we have no authority to say which specific setting is the most appropriate. The monitoring of level of care and

placement decisions under Medicaid rests solely with the State."

This lack of a "least restrictive environment" standard for placement is contrary to several federal statues enacted after the 1971 Medicaid Amendment allowing federal reimbursement to ICFs/MR. P.L. 94-142, The Education for all Handicapped Children Act (1975) requires that education be provided to all handicapped students in the least restrictive environment, or the environment in which handicapped students are with their non-handicapped peers to the greatest extent possible. The 1975 amendments to the Developmental Disabilities Act included a section entitled "Rights of the Developmentally Disabled". This bill of rights requires that developmentally disabled persons be provided treatment, services and habilitation in the setting that is least restrictive of the person's personal liberty. Thus, while federal policy is establishing a standard of serving handicapped persons in the mainstream of society, it is at the same time providing incentives to do the opposite.

Congress was aware of this situation when it passed the Home and Community Based Waiver Authority in 1981. Title XIX was amended to allow the Secretary of Health and Human Services to approve the use of Medicaid funds for home and community-based services for the aged, the physically disabled, the mentally retarded and the mentally ill. (24) Under an approved waiver, services, other than room and board, may be provided to mentally retarded persons who, but for the provision of such services, would require the level of care provided in Medicaid-supported institutions. Regulations implementing the waiver provision

include a cost formula which requires that a state's total Medicaid expenditures not increase with the waiver. (25) Services authorized by the waiver include case management services, homemaker/home health aide services and personal care services, adult day health, habilitation services, respite care services and other services as approved by the Secretary. States may be granted a waiver for three years initially. The waiver may be extended for an additional three years if services and conditions comply with program standards.

As of June 30, 1984, 33 waivers to serve mentally retarded persons had been approved for 30 states. For fiscal year 1984, plans submitted by states indicate that 15,114 MR/DD persons will receive waivered services. National cost data is not yet available on the waiver program.

Since the waiver program was authorized in 1981 and approved plans must be renewed every three years, waivers are just now coming up for renewal. States have expressed concerns regarding the terms of the renewal of the waivers and do not consider waivers as stable a source of funding as the traditional Title XIX Medicaid program, since it must be applied for separately, and is only authorized for a three year period.

On March 13, 1985, the final regulations governing the home and community care waiver were issued. These regulations create new obstacles for the states and fail to recognize the critical "active treatment" requirements of the ICF/MR program. The regulations declare that prevocational, and vocational training and educational activities may not be provided under the home and

community based services waiver and explain that individuals "would not in the absence of such services, require institutionalization." The regulations further state that we have "excluded these services because they are not cost effective alternatives to institutionalization." These regulations imply that either persons who are developmentally disabled cannot benefit from such services or the only obligation the federal government has to meet to such persons is to provide custodial care. The ICF/MR program was created 13 years ago to negate both assumptions and create a new level of care that was not being met for persons with developmental disabilities in ICFs and skilled nursing facilities. The critical component of the level of care required by the ICF/MR program is for active treatment, a much higher standard to be met than custodial care. The implementation of these regulations may well deny mentally retarded/developmentally disabled persons needed opportunities for growth.

There is no formal mechanism between the Department of Health and Human Services and the Department of Justice for sharing information, coordinating activities, or making referrals.

The Department of Health and Human Services is the agency which administers the ICF/MR program. Under the authority granted to it by the Civil Rights of Institutionalized Persons Act (CRIPA), the Department of Justice has the responsibility to investigate institutions which have demonstrated a reasonable cause for believing that conditions exist which deprive residents

of any rights or privileges protected by the Constitution or laws of the United States.

However, in a hearing before the Subcommittee on the Handicapped on Nov. 17, 1983, William Bradford Reynolds, Assistant Attorney General for Civil Rights, told Senator Weicker that he had not really been involved with HHS concerning ICFs/MR. Responding to questions from Senator Weicker in the July 1984 hearing, Secretary Heckler stated that HCFA staff and DOJ staff had met to discuss coordination between the two agencies.

In the fall of 1984 HCFA staff told Senate staff that they had met briefly with DOJ staff one year ago, but that there had been no follow-up. HCFA staff said that they were not, at that time, sending any information to the Department of Justice. At this briefing, one HCFA official said "the Justice Department takes too long" in conducting an investigation and cannot be relied on to respond to complaints relayed by HCFA.

Civil Rights of Institutionalized Persons Act

The U.S. Department of Justice continues to play a limited role in monitoring conditions in facilities for the mentally disabled as they relate to constitutional and federal statutory requirements. The few cases concluded by the Department's Office of Civil Rights suggests a continuation of the inactivity noted in previous congressional testimony.

Further, recently concluded investigations show that the Department's notice to the states as to findings have been sent up to 27 months after investigations are initiated. Such a lack of timeliness regarding matters determined to be egregious and flagrant abuses of the institutionalized mentally disabled potentially allows these conditions to fester, distorting the purpose of congressionally mandated intervention by the department.

In 1980, Congress enacted Public Law 96-247, the Civil Rights of Institutionalized Persons Act (CRIPA). (26) The Act provided the Department of Justice express statutory authority to investigate and initiate lawsuits on behalf of persons deprived of fundamental constitutional and federal statutory rights in state institutions. Fashioning the role played by the Department of Justice in cases brought to correct deplorable conditions and redress violations of rights, the Senate Judiciary Committee and the Conference Committee reports accompanying the legislation which eventually became CRIPA, both stated:

"One measure of a nation's civilization is the quality of

> treatment it provides persons entrusted to its care. The past decade has borne testimony to the growing civilization of this country through its commitment to the adequate care of its institutionalized citizens. Nowhere is that commitment more evident than in the actions of the United States Department of Justice." (27)

Since CRIPA's enactment, however, the role of the Justice Department in advancing the rights of the institutionalized has been questioned.

In 1971, in the case of Wyatt v. Stickney (28), Judge Frank M. Johnson invited the Attorney General to appear as litigating amicus curiae (friend of the court) to assist the court in gathering information on conditions and adequacy of treatment and care in an Alabama institution. Prior to the enactment of CRIPA, the Department of Justice participated in almost every major suit challenging conditions or violations of constitutional rights in mental institutions. Each case in which Justice had participated, according to the Senate Judiciary Committee report, had resulted in the court ordering immediate unconditional relief of conditions. Justice was also involved in such landmark cases as New York ARC v. Rockefeller (29), which resulted in a consent decree that ordered the depopulation of the Willowbrook State School for the mentally retarded and increased staffing levels, to provide for healthier conditions for those living in Willowbrook. Altogether, the Judiciary Committee report noted, Justice had been involved in more than 25 cases since 1971. In all of those cases, however, the Department's participation was

either as amicus curiae or intervening plaintiff, i.e. a third party to the suit. Never had the Department initiated suit successfully. (30)

In fact, two courts in which the Attorney General had tried to sue state officials had rejected the suits. In those cases, U.S. v. Solmon (31) and U.S. v. Mattson (32), the courts held that, absent specific statutory authority, the Justice Department did not have standing to bring suit. To remove these barriers to Justice initiating suit, Congress enacted CRIPA. As the Judiciary Committee report concluded, it was important to give the Department this authority because:

> "The resources and skill which the Attorney General brings to such litigation cannot be matched by private counsel. The Justice Department's access to the investigative resources of the FBI, the technical advice of other Federal agencies, and the professional assistance of nationally recognized experts in the field of institutional care, enable it to develop a comprehensive record for adjudicating courts. The experience and expertise of Justice Department attorneys guarantees that litigation will be handled professionally, with a minimal expenditure of judicial time and resources. The presence of the Attorney General lends credibility to the proceedings and alerts courts, litigants, and the public to the seriousness of the charges. Finally, the Department provides the stability and continuity necessary to see litigation to its conclusion and to monitor implementation of court decrees. These factors combine to make the Attorney General an invalu-

able aid to the judiciary and an indispensable advocate for the institutionalized." (33)

With respect to litigation as the means to redress institutional abuse the report concluded:

> "Neither the Attorney General nor the committee suggest that litigation by the Justice Department is an ideal method for eradicating widespread institutional abuse. It is costly, time consuming, and disruptive of the operation of State and local governments. Experience has shown, however, that it is also the single most effective method for redressing systematic deprivations of institutionalized persons' Constitutional and Federal statutory rights. Until such time as every State and political subdivison assumes full responsibility for protecting the fundamental rights of its institutionalized citizens, the need for Federal enforcement of those rights will continue."

After CRIPA's enactment, advocates for institutionalized individuals might have anticipated that the Department would use its resources to aggressively vindicate the rights of institutionalized persons. Under the Reagan Administration, however, some advocates have expressed disappointment with Justice's role.

Rather than the aggressive advocacy role that it historically had played, the Department has taken a very limited view of its role.

On Nov. 17, 1983, Senator Weicker chaired a hearing of the Senate Subcommittee on the Handicapped to examine allegations

concerning the abuse and neglect of mentally retarded persons. Assistant Attorney General William Bradford Reynolds testified at that hearing concerning the Department's activities under CRIPA. At that hearing, Reynolds explained his interpretation of CRIPA and the appropriate criteria for judging the Department's activities as follows:

> "In my view, CRIPA represents the basic congressional reaction to and remedial prescription for a record of tragic abuse and frustratingly slow action in individual lawsuits brought on behalf of institutionalized persons. But it is important to note at the outset that CRIPA does not define the civil rights of those who are institutionalized. Rather, it provides limited procedural authority for the United States to act when he discovers institutional conditions so 'flagrant and egregious' that they violate the Constitution. As in many other areas, Congress left it to the federal courts -- ultimately the Supreme Court -- to determine what constitutes a constitutional violation.
>
> "The Supreme Court has addressed this issue most recently in Youngberg v. Romeo, 102 Sup. Ct. 2452 (1982). In holding that the Fourteenth Amendment's Due Process Clause affords protection to the liberty interest of institutional residents, the Court set forth substantive guidelines which we try scrupulously to follow. In Youngberg the Court held that mentally retarded persons who are institutionalized enjoy several Fourteenth Amendments Rights: (1) the right to adequate food, clothes, shelter and medical care; (2) the right

to personal safety; (3) the right to freedom from unnecessary physical restraint; and (4) the right to such training as is necessary to further their interests in safety and freedom from undue restraint. On the other hand, Youngberg did not hold that states were under a federal constitutional obligation to provide the treatment necessary to cure the disorder or remedy the mental condition that prompted institutionalization, a question specifically reserved for later consideration.

"Accordingly, I perceive it to be our job -- a duty which I welcome and fully believe in -- to use the authority provided by Congress in CRIPA to compel states and local governments to stop confining frequently helpless citizens in conditions that offend both conscience and Constitution. The congressional authority is carefully and plainly delimited. Upon receipt of a colorable complaint the Attorney General is authorized and required to notify the appropriate state or local officials, to conduct an investigation and, if the evidence gathered persuades him there is a violation of constitutional protections, to so advise the responsible officials and attempt to arrive at an agreed-upon plan that would correct the deficiencies. If that is not possible, the Attorney General may then bring court proceeding to obtain relief, upon his certification that all reasonable steps short of court action have been taken.

"Accordingly, under the congressional scheme the measure of success is not how many lawsuits are brought -- for time

consuming litigation was one of the problems that concerned Congress -- but rather how many constitutionally intolerable situations have been remedied." (34)

Observers have criticized the Justice Department for its failure to diligently pursue enforcement of the rights of institutionalized persons by pointing out its limited use of its authority under CRIPA to bring lawsuits; for retreating and changing postions in suits previously filed; as well as taking a very narrow and limited view of its interpretation of court opinions articulating patients' rights.

One recent analysis of Justice Department activity in the field suggests that the Department is engaged in a concerted attempt to narrow the rights of the institutionalized mentally disabled.

The analysis was made by a former attorney with the Special Litigation Section of the Civil Rights Division of the Department, which has experienced a 100 percent turnover in the last two years:

"The Department's eagerness to change long-standing positions suggests a politicization of the litigation and enforcement processes that inevitably makes it a less credible participant in them. Its interpretation of Youngberg and its willingness to use it as a prism through which all matters arising in institutional litigation are viewed forces it into the ignoble position of rejecting all previous knowledge in the field and turning a deaf ear to new

and important developments. Thus, the Jackson treatment theory (where the Supreme Court said, 'At the least, due process requires that the nature and duration of commitment bear some reasonable relation to the purpose for which the person is committed.' ed.) is not viable, special masters are never appropriate, harm does not include regression, and community placement can never be constitutionally required, all because Youngberg did not explicitly sanction them. But, of course, these issues did not arise in Youngberg." (35)

Noting a philosophical gap between the Department and many of the advocates and critics of the Department, Reynolds at the hearing said:

"A sizable group of advocates in the mental health field do not see the Federal Government's role as the limited but effective one I have described. Rather, they are genuinely committed to the notion that Federal courts should require all institutionalized persons to be held under the least restrictive possible conditions, with many feeling that all institutional confinement should be eliminated. Under this approach courts would not be limited to correcting the kind of debilitating and life-threatening conditions identified by the Supreme Court in Youngberg, but instead would examine under a minimally restrictive standard, every aspect of institutional life. This approach thus necessarily focuses on court proceedings looking toward meticulous, detailed decrees.

> "As a personal view, I too, favor deinstitutionalization wherever possible, but as a Government official I do not believe that either Congress or the Federal courts have provided the authority to seek such solutions. Under our Federal system I maintain that the choice of whether to have institutional confinement be made by State and local governments; only when the conditions actually provided are in violation of Federal constitutional provisions should the Federal Government, in the person of the Attorney General, intervene. And that intervention, as Congress has prescribed, is for the Attorney General to notify the State, investigate the conditions, attempt to negotiate and monitor a remedial plan and, if necessary, to bring legal action to achieve the necessary relief to eliminate the specific, identified constitutional violation." (36)

Reynolds rebuttal to his critics is to point out the number of investigations that his office initiated. At the Subcommittee hearing Reynolds reported the Department had initiated 18 investigations of mental health facilities since CRIPA's enactment.

Reynolds attached to his testimony a list of the facilities and a brief descriptions of the status of those cases. The dates of Justice notification to the state officials of their intent to investigate allegations and the name of the facilities were:

- Nov. 5, 1980-East Louisiana State Hospital, Jackson La.
- Nov. 5, 1980-Rosewood Center, Owings Mills, Md.
- Nov. 5, 1980-Feliciana Forensic Facility, Jackson, La.

- March 23, 1981-South Florida State Hospital, Hollywood, Fla.
- July 31, 1981-Dixon Developmental Center, Dixon, Ill.
- April 19, 1982-Manteno Mental Health Center, Manteno, Ill.
- April 9, 1982-Enid State School and Pauls Valley State School, Enid, Okla.
- June 16, 1982-Logansport State Hospital, Logansport, Ind.
- July 1, 1982-Atascadero State Hospital, Atascadero, Calif.
- June 24, 1982-Orlando Sunland Training Center in Orlando, Fla.
- Aug. 18, 1982-Spring Grove Hospital Center, Catonsville, Md.
- Oct. 4, 1982-Worcester State Hospital, Worcester, Mass.
- Nov. 15, 1982-Northville Regional Psychiatric Hospital, Northville, Mich.
- Nov. 29, 1982, Hazelwood Intermediate Care Facility, Louisville, Ky.
- Feb. 7, 1983-Elgin Mental Health Center, Elgin, Ill.
- May 13, 1983-Fairview Training Center, Salem, Ore.
- Oct. 6, 1983-Central State Hospital, Indianapolis, Ill.
- Oct. 6, 1983-South Carolina State Hospital, Columbia, S.C. (37)

At the time of the hearing, all of these investigations were pending; no final resolutions had been reached with the states and the Department had not used its authority to bring suit in any of the cases. In one instance, they had joined suit as plaintiff intervenor involving Feliciana Forensic Center. Reynolds described his record as follows:

"Our experience shows that the conciliation process

can work most effectively. Rather than waiting years for the court battles to unfold before real relief comes to those who are institutionalized, we have already, through CRIPA conciliation procedures, achieved a great deal of success effectuating the rights of institutionalized mentally handicapped persons.

"For example, one of our cases had resulted in the closing of the Dixon Developmental Center for mentally retarded in Illinois. Following our investigation, the State authorities agreed that the conditions were constitutionally intolerable, and that the institution must be closed.

"A similar result was negotiated in portions of an institution in another case. In three other cases, remedial plans have been submitted by the States, one we have approved, and are now monitoring, and we are reviewing the other two.

"Three other investigations have been completed, and six additional ones are in progress. Moreover, we have notified two other Governors of our intentions to investigate. In two pending cases, local officials have obstructed our efforts to investigate, and litigation may well be required. A complete list of these activities is appended to my testimony." (38)

Commenting on the conciliatory approach of the Justice Department in response to a question for the record from Senator Weicker,

wrote:

"As a result of Reynolds' policy of conciliation, not a single enforceable agreement to eliminate civil rights violations has been negotiated with any mental retardation institution anywhere in the country. He claims that the closing of the Dixon Developmental Center came "(as) a result of our investigation and conciliation effort." He should be ashamed to tell such a blatant lie to a Committee of Congress. As Reynolds is well aware, the state's decision to close that institution had little if anything to do with the federal investigation. Dixon was closed in response to the exposure of abuses at the facility by the media, the recommendation of the state's own mental retardation professionals, and the desire of Governor Thompson to make the facility a prison. The Justice Department had barely begun its investigation and had conducted no settlement discussions with state officials when the decision to close Dixon was announced. That announcement came as a complete surprise to everyone at the Justice Department, including the line attorney responsible for the investigation, who learned of it by reading the headline in a newspaper.

"Not surprisingly, Reynolds can point to no additional successful results concerning any matter pursuant to the Act. Such a record of inaction sends a clear message to the operators of state institutions that the federal government will no longer play an active role in the enforcement of the civil rights of American citizens confined in state institutions." (39)

Addressing Reynolds interpretation of the law and his view of the role of the Department, Steve Whinston, also a former attorney in the Special Litigation Section of the Department said:

> "For ten years, the Justice Department argued to courts that institutionalized mentally retarded persons had a constitutional right to be placed in settings which are least restrictive of their personal liberty. Thus, institution residents should, wherever possible, be moved to more normalized non-institutional environments where they will be more able to receive the training needed to achieve meaningful habilitative objectives. Suddenly, under Mr. Reynolds, this was no longer considered to be consitutional right. Instead, for the first time, institutions were acceptable for large numbers of persons."

Whinston also pointed out that the Department has even changed its position in lawsuits in which it had been an amicus and sought remedies which plaintiffs attorneys were unwilling to accept.

> "The whole orientation of the Justice Department's litigation in this field has changed from enforcing the rights of the handicapped to establishing what are the limits of a state's obligations to the handicapped. The first question I was often asked under this Administration was 'What can we do to support the defendants on this issue?'
>
> "This greater concern for the state than the plaintiffs manifests itself not only in the substantive positions taken

by the Justice Department but also in the litigation strategy it pursues. The most blatant example of this was Mr. Reynolds' decision to exclude plaintiffs, on whose behalf the Department was supposedly litigating, from settlement negotiations.

"This first happened in the landmark Wyatt case. There, Mr. Reynolds personally conducted negotiations with representatives of the State of Alabama from which representatives of the plaintiff and his own trial attorneys were excluded. The Justice Department eventually signed a separate agreement with the State that was unceremoniously rejected by the District Court.

"A similar tactic was pursued in a case on which I worked, the Mansfield Training School litigation. There, negotiations began in earnest in early 1983. As the May, 1983 trial date approached, the negotiations became difficult and contentious although discussions continued. At some point, I was advised by Mr. Reynolds through my supervisor that no matter what happened in the negotiations we would not participate in trial. I was instructed to prepare a separate settlement agreement to be signed by the State and the United States. This agreement was to be based on the State's latest proposal, which had been rejected by the plaintiffs, with certain key elements (a schedule of deinstitutionalization, outside monitoring of progress, and assistance to retarded persons involved in due process hearings) omitted. I was instructed to mail this agreement to the State's attorneys

but to keep even its existence a secret from plaintiffs' counsel. The only reason such a document was not signed in that case was that the Connecticut Attorney General had the good sense to realize that it was legally irrelevant to sign a 'settlement' with Justice if he still had to litigate against plaintiffs.

"This overeagerness to settle, even to the extent of excluding plaintiffs from negotiations, is not a characteristic of an advocate. Rather, it demonstrates and illustrates the motivating concern of today's Justice Department -- to ease up on the states and to ease off on asserting the constitutional rights of the handicapped.

"Of course, this should not be. The handicapped are the most sympathetic and the least political of the Department's client groups. To support the handicapped one need not refer to divisive factors of race, religion or income. Handicapping conditions cut across all those lines. To support the handicapped one need not impose the Federal government on anyone's private life. Recognizing the rights of the handicapped exalts the values of the individual above the authority of the state. This should appeal to any administration, even a conservative one. But that has not been the case here. Their visceral ideological opposition to enforcing civil rights extend to all aspects of civil rights, even to the handicapped.

"This attitude has been recognized ir the field. The Justice Department, once a sought after ally of

plaintiffs, is now shunned by plaintiffs. Its participation is no longer valued. Groups refuse to cooperate with Justice's investigations. In cases where Justice is already involved, plaintiffs employ tactics designed to keep Justice out of certain issues. In sum, the Justice Department under Mr. Reynolds has completely lost its credibility as an advocate for the handicapped. In my view, this is also beginning to happen with the courts as well. Judges recognize that Justice's views are tainted by partisan ideology rather than distinguished by legal scholarship. This process will take many years to correct even after Mr. Reynolds' departure." (40)

In discussions with Senate staff, Whinston's experience was confirmed by a plaintiff's attorney in the Mansfield case. He told Senate staff that the Justice Department had promised the court that it would use its resources to prepare witnesses and interrogatories for suit. This was before the change of administration. After the Reagan Administration took office, Department attorneys simply filed appearances in court but nothing more. Pointing out Justice's inclination to settle lawsuits, he stated that when the Department files suit or intervenes, they come in with their consent agreement already drafted.

On Jan. 9, 1985, Senator Weicker wrote to the Justice Department and requested information concerning complaints about conditions in mental health facilities received by the Department. The letter asked for an update on the Department's

activities since the Handicapped Subcommittee's 1983 hearings. The following response was given to that request in a Feb. 5, 1985 letter from Justice:

> "We are unable to respond fully to your request but we can offer a brief explanation of how the Special Litigation Section reviews complaints and other information about alleged violations. The Special Litigation Section receives information about alleged constitutional or statutory violations in public and private institutions from many sources, including, for example, various requests from individuals to investigate private institutions, and complaints about conditions which do not reach the level of egregious or flagrant conditions contemplated by the Act. All of these complaints and other information about public institutions regardless of merit, are reviewed and dealt with appropriately. Those which on their face appear to describe legitimate or serious concerns are looked into further to determine whether formal investigation is required. The volume of information is so great and the level of seriousness so varied, however, that we cannot maintain records of each and every item of information that comes to our attention. For these reasons, it is not possible to retain or track each and every complaint or piece of information which the Section receives for its review."

The Department further reported that since the November 1983 hearing, seven of the 18 pending investigations/negotiations had been closed: In two instances, Rosewood, Md. and Logansport and Central State, Ind., consent decrees had been entered into with

state officials. Previously, the Department had reported that at Feliciana in Jackson, La., a settlement had been reached among the parties and at Dixon Developmental and Orlando Sunland Training School, they had no further involvement because of progress by the state in correcting the deficiencies; and since the hearing, six more mental health and retardation centers were being investigated under CRIPA. Those facilities and the date of Department's notification to state officials were:

- Nov. 11, 1983-Ypsilanti Regional Psychiatric Hospital, Ypsilanti, Mich.
- Dec. 16, 1983-Wheat Ridge Regional Center, Denver, Colo.
- Feb. 22, 1984-South Beach Psychiatric Center, Staten Island, N.Y.
- May 1, 1984-Southbury Training School, Southbury, Ct.
- Nov. 30, 1984-Belle Chasse State School, Belle Chasse, La.
- Dec. 7, 1984-Fort Stanton Hospital and Training School, Fort Stanton, N.M.

In sum, as of February 1985, the Department had initiated a total of 24 investigations. Three of these resulted in consent decrees and five were closed. According to information supplied by the Department then, 16 of 24 investigations remain pending. Senate staff independently obtained two recent letters of the Department's investigative findings involving cases with negotiations still pending.

On Nov. 26, 1984, the South Carolina Department of Mental Health made public a letter from Reynolds to Governor Richard C. Riley concerning the Justice Department's findings from its investigation at South Carolina State Hospital. The

investigation had commenced on Oct. 6, 1983. The findings included the following:

"Staffing and Staff Qualifications: Our consultants found serious deficiencies in the number of qualified physicians at SCSH. As of April 1984, 28 physicians were responsible for round-the-clock coverage of almost 1100 patients. Not all of these physicians were full time, and some were not qualified in certain areas critical to the proper medical treatment of mental health patients, such as the use of psychotropic drugs. Of the 28 practicing physicians, 18 are psychiatrists. While some had a manageable caseload of 20 to 25 patients, others were responsible for the psychiatric treatment of up to 60 to 80 persons. Similarly, there is an inadequate number of psychologists on the staff. As discussed below, these staffing deficiencies have unconstitutionally deprived SCSH residents of adequate medical care and treatment necessary to avoid undue risks to the patients' personal safety and to assure freedom from unreasonable bodily restraints.

"We also found inadequacies in nursing coverage throughout most of the hospital, especially during the evening and night shifts. While some wards apparently have better coverage than others, our consultants noted instances in which one Registered Nurse was covering up to 14 wards, including three forensic wards.

"In conclusion, we believe that the current complement

of professional and direct care staff is not sufficient to assure that professional judgments are being exercised in decisions affecting patients at SCSH.

"Protection from Harm: The deficiencies discussed above have resulted in serious deprivations of the right of patients to be free from unreasonable risks of bodily harm. Patients suffering from severe and sometimes violent psychiatric disorders, who are inadequately or inappropriately treated and supervised, pose a significant danger to themselves and others. Our review of Patient Abuse Reports, dating from January 1982 through January 1984, and of Board of Inquiry records, dating from July 1976 through January 1984, fully supports our finding that these deficiencies subject the patients to unreasonable personal safety risks. These include risks of deaths or injury from patient assaults, aspiration of gastric contents, choking on food, suicide, and improper medical diagnosis and treatment.

"Use of Psychotropic Drugs: Our consultants noted serious deviations from accepted professional medical practice in the use of psychotropic drugs. Several physicians interviewed were not well trained in psychopharmacology. For example, a number evidenced difficulty in discriminating between tardive dyskinesia and extrapyramidal side effects. This creates a clear danger to patients since the appropriate drugs to treat acute extrapyramidal side effects might exacerbate the condition of tardive dyskinesia. Some physicians were not aware of the

neuroleptic malignant syndrome which is a potentially fatal condition occurring in some patients receiving antipsychotic drug treatment.

"While the prescription of several drugs at one time may be appropriate in some circumstances, review of patient records and Board of Inquiry reports revealed numerous instances of inappropriate polypharmacy. Additionally, almost all the patients at SCSH whose charts were examined were on some form of medication, but in many charts the goals and indications for drug treatment were not clear and reasons for changes in medication or dosage were not articulated. These problems are compounded by the reliance on inadequately qualified and supervised direct care staff to administer medication. Overall, the prescribing, administering, and monitoring of psychotropic drugs at SCSH constitute a substantial departure from accepted professional practices.

"Restraint and Seclusion: Restraints have been ordered on a nonemergency PRN basis for extended periods without professional evaluation by a physician. In the case of the Forensic Unit, Ward 176, the practice of secluding virtually all patients PRN in nonemergency situations is an extreme example of improper medical treatment which involves SCSH's own standards for issuance of seclusion orders.

Treatment necessary to facilitate the ability of patients to function free from unreasonable bodily restraint is often not provided. The staffing deficiencies previously discussed contribute to the failure of SCSH to provide such

patients with necessary treatment and thus to the concomitant improper use of seclusion and restraint.

"Dates of Occurrence: While it is possible that the above-described conditions have existed for a longer period, our review of records which you have provided, including Board of Inquiry reports, indicates that a pattern or practice of constitutional deprivations has existed since at least 1977."

On Feb. 27, 1985, the Michigan Department of Mental Health made public a letter from Reynolds to Governor James J. Blanchard concerning an investigation of Northville Regional Psychiatric Hospital. The investigation had commenced on Nov. 15, 1982.

The findings included the following:

"1. Staffing

"Staff deficiencies pervade all major disciplines at NRPH, and result in patients being deprived of minimally adequate medical and psychiatric services necessary to avoid undue risk to their personal safety and ensure freedom from undue bodily restraint. The number of qualified psychiatrists at NRPH is insufficient. The lack of qualified psychiatrists means that patients are subject to inappropriate medical treatment due to incorrect diagnoses, harmful medication practices, increased use of seclusion and restraints, and insufficient monitoring of nonphysician staff who are responsible for carrying out important medical procedures.

"NRPH is also severely lacking in the number of qualified psychologists, with only two psychologists responsible for over 1,000 patients. Consequently, important diagnostic assessments regarding patients' psychiatric conditions are not made, and treatment programs necessary to preserve patients' safety and freedom from undue bodily restraint are not provided.

"A nursing staff shortage presents a major problem at NRPH. While patient capacity is 1032, the census was 1100 on our last tour on July 25-26, 1984. The inadequate nursing staff was evident throughout our tours, with most wards over census and understaffed. During evening and night shifts one RN would have the responsibility of covering up to 2 or 3 buildings, containing between 4 and 6 wards, with up to 240 patients. The result is that the care being provided by the present nursing staff to the 1100 patients at NRPH is clearly inadequate and jeopardizes patient safety. Indeed, a professional staff member indicated that the present nursing staff was capable of providing rudimentary custodial care to only 700 patients. The nursing staff shortage also results in unqualified and inappropriately trained personnel carrying out important medical procedures, thereby increasing the threat of unreasonable risk of harm to NRPH patients.

"Our consultants found the above staffing shortages to result in severe deficiencies in NRPH's practices with regard to psychopharmacology, recordkeeping, seclusion and restraint,

and the hospital's ability to provide treatment programs to those patients for whom such programs are necessary to ensure their protection from harm and freedom from unreasonable bodily restraint.

2. Medical and Administrative Practices

"Our consultants found that severe deficiencies exist in all areas of psychopharmacology at NRPH, including the prescribing, administering and monitoring of psychotropic drugs, as well as the hospital's recordkeeping practices in relation to the above.

"Drugs are most frequently administered at NRPH by resident care aides (RCAs) - attendant care staff. The insufficient number of RN's, as described above, means that untrained, unqualified, and inexperienced staff are dispensing potent medications, including intramuscular injections, under limited or on some shifts nonexistent supervision. This practice, which is a significant departure from accepted medical judgement, increases the risk of morbidity and mortality due to medication error. The fact that important medical procedures and treatment decisions are made in the absence of the exercise of qualified professional judgments by physicians and RN's subjects patients to unreasonable risks of harm to their personal safety.

"There is also a pattern at NRPH of a lack of documentation justifying the reason for the prescription of particular

medication, patient response to the regimen of drug therapy, and changes in medication. Progress notes are frequently unavailable on identified problems and when they are available, they are often illegible. Additionally, the criteria upon which diagnoses are based are often not listed in the patients' charts and when diagnoses are made they are rarely reconsidered. Such inadequate recordkeeping makes it impossible to make medically appropriate and reasonably safe treatment decisions and is therefore a significant departure from accepted medical judgement.

"Another deficient psychopharmacological practice is the inappropriate screening and monitoring of drug side effects, particularly tardive dyskinesia (TD), an antipsychotic drug induced neurological side effect caused by long term treatment.

"3. Seclusion and Restraint

"Seclusion is widely used at NRPH, frequently without doctors' orders and sometimes without the involvement of any licensed medical personnel, demonstrating the absence of the exercise of professional judgement by qualified physicians and nurses in the use of this procedure. The most frequent reason for secluding or restraining NRPH patients is patient on patient abuse. Upon a review of patient charts and interviews with patients, our consultants determined that seclusion and restraint are used more for punishment or for the convenience of staff instead of for treatment. Our consultants

could not identify any treatment programs afforded to patients to reduce or eliminate the need for seclusion or restraints. The found that the lack of staff, as outlined above, was a major factor resulting in NRPH's inability to provide necessary treatment to its patients in order to ensure them freedom from unreasonable bodily restraint, including seclusion. In the view of NRPH's own professional staff, seclusion and restraint are used unreasonably when treatment, if afforded, might obviate any need for its use.

"4. Protection from Harm

"Patients who suffer from severe and sometimes violent psychiatric disorders, who are inadequately or inappropriately treated or supervised, pose a significant danger to themselves and others. Our review of incident reports, dating from July, 1983 to May, 1984, supports our finding that the above deficiencies subject patients to unreasonable safety risks. These include attacks by patients on other patients or staff, self abuse, destruction of property, neglect of patients who are supposed to be under one-on-one observation, inappropriate medical treatment, and unreasonable use of seclusion and restraint. The deficiencies discussed above have resulted in serious deprivations of the right of NRPH patients to reasonable security and safety from harm, as well as freedom from unreasonable bodily restraint, including seclusion."

A section-by-section comparison of the remedies sought by Justice at the facilities reveals the general nature of the

prescription "to bring each of these conditions to the minimum level required by the Constitution of the United States."

South Carolina: "1. Hiring sufficient numbers of qualified psychiatrists, and other trained professional and direct care staff to ensure, on a continuing basis, that patients are provided with minimally adequate medical care and are not subjected to unreasonable risks to their personal safety."

Michigan: "1. Hiring sufficient numbers of qualified psychiatric nurses, and other trained professional and direct care staff to ensure, on a continuing basis, that patients are provided with minimally adequate medical care and are not subjected to unreasonable risks of harm to their personal safety.

South Carolina: "2. Development of a system through which the appropriateness and safety of patient medical care, particularly psychopharmacological treatment, can be monitored. In this regard, the state should develop and enforce requirements for more stringent recordkeeping; for physician review and approval of assessments and decisions relating to medical care made by nonphysician staff; for recording complete and detailed background information and clinical observations relative to the medical care of patients; and for ensuring that there exists for each patient a record of the course of treatment anticipated and followed, including individual problems and treatment goals. Appropriate equipment to meet necessary medical emergency needs should be obtained."

Michigan: "2. Development of a system through which the appropriateness and safety of patient medical care can be monitored by an experienced and qualified staff. In this regard the State should develop and enforce requirements for minimally adequate recordkeeping and for physician review and approval of assessments and decisions relating to medical care made by nonphysician staff."

South Carolina: "3. Development and implementation of guidelines for the appropriate use of seclusion and restraint."

Michigan: "3. Development and implementation of guidelines for the appropriate use of seclusion and restraint."

South Carolina: "4. Development and implementation of such treatment programs as are reasonably necessary to promote patient safety and to keep patients free from undue bodily restraint, including seclusion."

Michigan: "4. Treatment programs must be professionally designed for those residents for whom such treatment will reduce or eliminate unreasonable risks to their personal safety and/or the need for undue bodily restraint. Immediate attention must be given to residents with self-injurious, aggressive, and other destructive behaviors by identifying them and implementing necessary treatment programs."

South Carolina: "5. Development and implementation of measures adequate to assure staff compliance with hospital policies, protocols, and standards of job performance and behavior relating to the areas discussed above."

Michigan: "5. Development and implementation of measures adequate to assure staff compliance with hospital policies, protocols, and standards of job performance and behavior relating to the areas discussed above."

Finally, after describing conditions that "threaten the health and safety of patients" at Northville in Michigan and "represent grave dangers to the health and safety of patients" at South Carolina State Hospital; and further, prescribing the hiring of "sufficient" staff and the development of unspecified "systems," "guidelines," "treatment programs," and "measures," the Justice Department recommended further meetings to develop plans of correction.

South Carolina: "I would note that many of our findings and recommendations will come as no surprise to SCSH personnel. Many of these individuals candidly acknowledged the existence of areas requiring improvement. As previously noted, it was clear to us that SCSH employs many conscientious and dedicated staff who strive to provide the best care possible. We would be remiss if we failed to commend these persons for their very substantial efforts.

"Again, we want to thank you for your cooperation.

Our attorneys will be contacting your office shortly to discuss this matter and to arrange for future meetings. They will be able to provide your staff with more detailed information.

"We would also be happy to make our consultants available to help the state formulate a specific and detailed plan for effectuating whatever corrective measures the state may choose to utilize in achieving constitutionally adequate conditions at SCSH."

Michigan: "I would note that many of our findings and recommendations will come as no surprise to NRPH personnel. Many of these individuals candidly acknowledged the existence of areas requiring improvement. It was clear to us that NRPH employs many conscientious and dedicated staff who strive to provide the best care possible. We would be remiss if we failed to commend these persons for their very substantial efforts.

"Again, we want to thank you for your fine cooperation. Our attorneys will be contacting your office shortly to discuss this matter further. They will be able to provide your staff with further detailed information. We would also be happy to make ou consultants available to help the State formulate a specific and detailed plan for effectuating a legally binding, judicially enforceable agreement with the United States in achieving constitutionally adequate conditions at NRPH. Information about federal financial assistance which may be available to assist with the remediation process can be obtained through the United

States Department of Health and Human Services' Regional Office (Michele Harris, Director, Intergovernmental and Congressional Affairs; (312) 353-5132) and through the United States Department of Education by contacting individuals listed in the attached information guide. I look forward to working with you in a spirit of full cooperation to resolve these matters."

One of the facilities where the Department of Justice was investigating but had not initiated suit was against the Rosewood Center in Owings Mills, Maryland, coincidentally the same institution where Justice had been denied standing to sue in 1976 prior to enactment of CRIPA. In a Feb. 19, 1982 letter to Governor Harry Hughes of Maryland, Reynolds cited conditions that caused residents of Rosewood grievous harm. He cited their major areas of concern as: "abuse and neglect of residents minimally adequate environmental conditions and inappropriate placement of residents." The letter detailed the following specific findings on conditions at Rosewood by Justice investigations:

"Rosewood has identified 777 persons in need of, and not receiving occupational therapy services.

"Six severely handicapped female residents of Johns Cottage were allegedly raped by an outside intruder. It is undisputed that several of the residents had positive tests of gonorrhea of the throat right after the incident.

"The charts of several male residents show the presence of venereal disease.

"Rosewood incident reports show that in June 1980, an employee of Gundry Building took a Rosewood resident off grounds without permission, and sexually abused him.

"In March 1980, nonconsensual sexual contact occurred between one resident, and at least one, and possibly three residents of the Stump Building. This incident occurred while the direct care staff person on the unit was sleeping.

"At least two deaths in 1980 were due in part to inadequate supervision by the Rosewood staff. As you probably know, Attorney General Sachs has reported on one of these deaths to the Maryland Humane Practices Commission.

"In February 1980, William Tillman managed to obtain a set of keys from a direct care staff person, and escaped from Rosewood; he was found near Rosewood by some passerby nine days later, dead from exposure to the cold. Two staff scheduled to be on duty the evening of Tillman's escape were not present. Robert Haynie, who was profoundly retarded, died on September 5, 1980, when a staff person left him unattended in a bath.

"Moreover, we have recently learned of the death of a resident of Benzinger Cottage. The resident apparently died as a result of being pushed down a flight of stairs. In our judgment, residents are exposed to serious harm at Rosewood.

"The vast majority of Rosewood clients reside in inadequate, deteriorating buildings. These residents are sterile, crowded, noisy places, which fail to provide even a modicum of privacy. The stench of urine is prevalent in a number of buildings.

"In the Pembroke Building, residents, many of whom have ambulation problems, were expected to cross over the puddle created by overflowing toilets, to reach the few working toilets. Severe heating problems in the Richards Building forced clients to sleep in their overcoats.

"During the recent cold wave, residents in Gundry, Richards and Pembroke Buildings were subjected to subfreezing temperatures.

"For many Rosewood residents, their environment not only fails to provide a homelike atmosphere, it jeopardizes their health and safety. For example, the 65 severely physically handicapped, and mostly wheelchair-bound residents of the second floor of the Wyse Building would have great difficulty evacuating the building in the event of a fire, and indeed, a fire did occur in Wyse last winter."

The letter suggested the following corrective actions:

"Rosewood must take steps to provide for full implementation of resident's individualized program plans.

"Needed professional and direct care staff must be hired.

"Rosewood must reduce the level of abuse and neglect in the institution.

"The institution must devise a preventive maintenance plan to deal with the deficiencies of the various buildings."

In the face of the abuses cited above, Reynolds closed the letter saying "we are willing to discuss these issues with you in greater detail at your convenience [emphasis added]."

On Jan. 17, 1985, Justice filed a consent agreement with the state of Maryland in district court to correct the conditions at Rosewood. This "settlement" came nearly three years after the letter to the Governor reporting Justice's investigation findings and nine years after the district court had dismissed a suit brought by Justice at the same institution.

The general principles of the agreement require that medical treatment, training and self-care skills of all residents (i.e. toileting, feeding) shall be made based on qualified professional judgments, all residents will be given appropriate care and medical treatment, all residents will receive reasonable training to prevent unreasonable risks of harm and undue restraint and that the physical environment be maintained to protect residents from unreasonable risks of harm or personal safety. To achieve these goals, the agreement calls for the state to take specific actions to: increase staffing, including physicians, psychologists, registered nurses, licensed practical nurses and direct care workers in ratios as set out in the agreement; and submit a plan within a set time frame on how it

will achieve these goals.

It was Nov. 7, 1980 when the Justice Department notified Maryland officials of its intent to investigate the conditions and treatment of the mentally retarded residents at Rosewood. It was approximately 15 months later, that the Department wrote to the Governor conveying their findings. Not until Jan. 17, 1985, 50 months after initiating investigation and almost three years after informing the governor of its findings, did Justice reach a settlement and enter a consent decree with the state. The letter from the Department recognized that these conditions existed since 1974. Even though the 1976 lawsuit involved another administration, it has taken more than 4 years for this administration in its "conciliatory approach" to reach a settlement.

The time lag between the finding of unconstitutional conditions at Rosewood and the settlement designed to ensure that corrections are made shows, at the least, that the Department's conciliatory approach in this case and others has the potential to negate the type of federal involvement in basic health and safety issues envisioned and mandated in CRIPA.

The Future

Institutionalization and the Mentally Ill

The single most visible public issue regarding mental health in the nation today is that of homelessness. Public notions of "bums" and "hobos" as the infantry of the homeless have been largely replaced by the idea that many of these individuals are in fact refugees from mental health care, victims of psychiatric or legal mistakes, lured away from their safe institutional berths for unexplained reasons.

In Boston, an estimated 95 percent of the city's 2,000 homeless are said to be mentally ill by one estimate. In Washington, D.C., the estimate is up to 50 percent of the men and up to 90 percent of the women are mentally ill out of a homeless population of between 5,000 to 10,000. In New York City, thought to have the nation's highest homeless population, estimated at some 50,000, the percentage of mentally ill homeless is said to top 50 percent.

Nationally, a third or more of the 300,000 to 2 million homeless are said to have experienced some form of mental illness.

Over the last several years advocates for the homeless have noted the increasing numbers of those needing help who are mentally ill, many of whom are former residents of state mental hospitals.

"Over the last two decades, the wholesale and careless

depopulation of mental institutions has perverted the implementation of the judicially-mandated right not to be confined if one is not a danger to oneself or others. By the hundreds of thousands, mental patients who have been aided by legal precedent and the advent of therapeutic drugs have been released to the streets, often with no more than a bus token.

This explosion of mentally fragile people returning to society occurs without the assistance and community support services that were ordered for them. The criminal lack of aftercare for such people has meant that their lives are often on display for the rest of us, contributing to one of the more popular images of the homeless: the woman or man, aimlessly wandering and animatedly talking, perhaps to an unseen companion." (41)

Allegations of careless and wholesale discharges from state institutions continue.

In December 1984, the Houston Post reported that some two dozen persons per week were taken from Austin State Hospital in Texas and "discharged" at a bus station in Houston. Most of the ex-patients were left with no money and no provision for food or shelter. A bus station security guard, the newspaper reported, escorted the twice weekly vanload to a local mission.

The Texas mental health system is under federal court order to hire more staff for the eight mental hospitals or discharge more patients.

Recently, the issue of the homeless has exploded into a

full-scale public debate. Much of the debate is local, concerning the cost of services, the location of shelters in neighborhoods and the public policy of even allowing rootless individuals to roam a community.

The debate is also carried on between the legal and psychiatric professions, who have freely blamed each other for excesses over the years and in some cases, see this issue as the battleground of the next stage of care of the mentally ill.

The situation was brought into sharp focus this year, even before the annual spate of stories about the plight of the wintertime homeless, by a report published by the American Psychiatric Association. The report was entitled "The Homeless Mentally Ill" and it describes homelessness as one of the tragic effects of deinstitutionalization, a policy aided in a major way, the authors say, by the legal profession's zealous advocacy of patient rights. In the minds of the APA authors, lawyers and advocates share a heavy burden of blame for this failed policy.

That is, these advocates, in seeking to protect the rights of patients in the face of admittedly abusive conditions in mental hospitals by seeking their release, failed in a greater responsibility to safeguard the patients from some of the most debilitating effects of mental illness.

But remedying this past overbalance favoring the legal rights of mental patients should not be seen as an argument for reinstitutionalization of the mentally ill, several APA authors wrote.

The APA report notes that "Society has a limited tolerance of mentally disordered behavior, and the result is pressure to institutionalize persons needing 24-hour care wherever there is room, including jail." (42)

The director of the National Coalition for Jail Reform, said in a newspaper interview in 1983 that more than 600,000 mentally ill and retarded persons were in jails in 1982. "Moving mentally ill persons out of institutions in the 1970s may have been a good idea, but in many cases 'the money has not followed the people,' she said. 'For many, one kind of institution -- the mental hospital -- has been replaced by another institution -- the jail.'" (43)

Further, the APA report notes, "Some professionals now talk about sending the entire population of chronically and severely mentally ill patients back to the state hospitals, exaggerating and romanticizing the activities and care the patients are said to have received there. To some, reinstitutionalization seems like a simple solution to the problem of deinstitutionalization such as homelessness. But activity and treatment programs geared to the needs of long-term patients can easily be set up in the community, and living conditions, structured or unstructured, can be raised to any level we choose - if adequate funds are made available." (44)

But in the absence of alternative placements, the APA warns, public sentiment could propel reinstitutionalization. "There is a growing backlash from some concerned segments of the community

about the lack of evidence that deinstitutionalization really works. If some corrections were made now, we might avoid a groundswell of opinion that could again make state hospitals the primary locus of care. Perhaps it is time that patients' rights groups and civil liberties lawyers focus more on the rights of patients to housing and care in the community...and less on forcing discharges from hospitals, which may ultimately put people on the street." (45)

A significant part of the discussion about solutions for the homeless mentally ill centers on the need perceived by some medical professionals to restrict the freedom and thereby staunch a psychiatric deterioration of this population. The issue is usually raised in the press and professional literature under the heading of asylum, a word associated with the "moral treatment" reforms in care of more than 200 years ago. The word also connotes institutionalization.

Dr. Charles Krauthammer, a psychiatrist and journalist, wrote recently that the homeless are overwhelmingly mentally ill and that sheltering them is only one solution. "There is a better alternative, however, though no one dares speak its name. Asylum. A place where the homeless mentally ill are taken and given food, shelter, hygiene and a sense of order in their lives."

He said the word "conjures up the snake pit," but actually "means taking people away to be cared for, whether they like it or not. That means taking control...and that means violating their rights, as currently defined...There will be a lot of

thundering from civil libertarians. But it certainly can be done." (46)

Little more than a week later, the article was answered in the same newspaper by an attorney for the Mental Health Law Project, Leonard S. Rubenstein.

"The revived idea of asylum reflects a pessimism about society's willingness and ability to provide what a homeless person needs," Rubenstein wrote, "whether afflicted with a mental disorder or not. Bowing to that pessimism shows poverty of thought."

The reality of asylum, "is rigid confinement. The hospital may serve a function in providing acute, short-term care (and even for this there are often better alternatives), but for the long-term patient it remains at best a place of endless idleness, locked wards, isolation cells and deprivation of normal human contact." (47)

Away from this historic battleground of lawyers and psychiatrists, the landscape still forms a clear if uneven path to take the mentally ill from the streets to the hospitals.

The National Institute of Mental Health has said the latest figures available show approximately 50 percent of the nation's mental health money is spent on hospitalization and annual combined expenditures for state hospital care are approximately $4 billion.

In 1978, the President's Commission on Mental Health noted

the incentives provided by federal spending: "Sometimes, inappropriate placements are forced upon the chronically mentally disabled by the restrictive nature of the regulations that govern distribution of Federal monies. A specific example is afforded by Medicaid funds which are not available to patients aged 21 to 65 in public or private hospitals. Thus, the level and type of care given to the chronically mentally disabled is frequently based on what services are fundable and not on what services are needed or appropriate. This not only does a disservice to disabled individuals but also distorts Federal expenditure patterns in various categorical programs." (48)

The recommendation made by the Commission was to provide care to the chronically mentally disabled regardless of age or place of residence.

Private health care money also provides a bias toward hospitalization, according to Dr. Charles A. Kiesler of Carnegie-Mellon University, who argued in a 1982 study against basing public policy on outdated "myths" surrounding hospitalization issues.

"People are being treated in more costly and less effective environments because it is the only treatment alternative the insurance plan will pay for, or at least pay for completely," Kiesler wrote. "A plan that considered the total cost and the patient's welfare might do better to set up financial and professional barriers against hospitalization rather than incentives favoring it."

Noting the dwindling national data base for hospitalization information, Kiesler compared statistics from NIMH and the National Center for Health Statistics.

The figures show "Mental hospitalization is increasing well in excess of the population rate," Kiesler found, although "the site of hospitalization has changed dramatically. The public image of mental hospitalization--the state mental hospital and the private mental hospital--now accounts for only 25 percent of the total incidence of mental hospitalization." (49)

Despite significant declines in the use of state/county mental hospitals, some 25 percent of total hospital days in the United States are for mental disorders. The figure has remained steady, Kiesler writes, because of the sharp, "linear" increase in the use of general hospitals as sites of hospitalization for mental disorders, especially those without psychiatric units.

Many professionals in the field call this shift of patients from state mental hospitals to other facilities "transinstitutionalization," or moving the site of care from one institution to the next as opposed to independent or quasi-independent living in the community.

"...thousands of former patients now live in nursing homes, board and care homes, adult homes and other institutional settings in the community. These mostly private, profit-making facilities serve the custodial, asylum and treatment functions that were once performed almost exclusively by state mental hospitals. The growth of what has been characterized as social

control entrepreneurialism has thereby perpetuated the segregation of the chronically mentally ill in a new ecological arrangement in the community. Numerous reports also indicate that many other patients are now incarcerated in local jails and correctional facilities." (50)

Despite the general movement away from the state mental hospitals that occurred through the 1970s, "Data from the National Institute of Mental Health indicate that new chronic patients have continued to accumulate in state and county mental hospitals throughout the country, and statistics from New York and several other states show a reversal in the downward trend of the overall resident census in public mental hospitals. These trend reversals preceded the fiscal limits of the early 1980s, but a recent analysis suggests that current budgetary restrictions are likely to increase institutionalization." (51)

Furthermore, following the 1981 Omnibus Budget Reconciliation Act, which repealed specific funding for community-based treatment of the chronically mentally ill, recent policies could provide new incentives for hospital care.

> "In 1983 the Medicare Prospective Payment System was inaugurated. The enabling legislation authorized payment for hospitalization prospectively on the basis of preestablished rates for specific "diagnosis-related groups" (DRGs) rather than retrospectively on the basis of actual costs. Although designed to save Medicare resources in the Hospital Insurance Trust Fund by reducing the length and cost of hospitalization, the prospective payment system

could also increase pressure on public general hospitals and long-term care facilities to provide for patients who might be discharged prematurely by other institutions on fiscal rather than clinical grounds. Such clinically irresponsible behavior would lead to a shifting of costs rather than a savings of resources and would counter the trend away from unnecessary use of institutional services. Because of a lack of experience in and general uncertainty about applying DRG based systems to mental disorders, psychiatric hospitals and psychiatric units in general hospitals were excluded from the prospective payment system until the applicability of DRG to inpatient psychiatric care and treatment could be evaluated." (52)

The incentive for various levels of hospitalization in one state, New York, was noted in the August 1984 draft report of the Governor's Select Commission on the Future of the State-Local Mental Health System:

"Reliance on the Medicaid program as a principal source of funding has resulted in cost shifting among levels of government and in a highly medicalized mental health network. The Medicaid formula in New York is based on 50-25-25 percent federal/state/local cost sharing. Although federal regulations prohibit Medicaid reimbursement for persons 22 to 64 in State mental hospitals, it is available in general hospitals. Since the state pays 100 percent of the costs of care in State mental hospitals for this age group, there is a fiscal incentive for the State to promote inpatient

psychiatric care in general hospitals. Conversely, local governments have a fiscal incentive to promote inpatient care in State mental hospitals since the State pays 100 percent of such costs. Consequently, State and local mental health authorities may operate at cross purposes, with financial considerations taking precedence over patient needs. The Medicaid programs incentives for use of general hospitals as a primary site of treatment conflict with the basic tenets of sound community mental health care which emphasize alternatives to hospitalization." (53)

In the meantime, federally-supported outpatient care, the type of care sought most for the mentally ill by medical professionals and advocates alike, is largely unavailable.

In testimony prepared for the U.S. Senate Special Committee on Aging last December, John A. Talbott, M.D., president of the APA, said, "Without insurance, whether Medicare or Medicaid, outpatient treatment becomes virtually unobtainable. There are few dollars which would have been utilized at the state facility which follow the patient. Medicare and Medicaid (in most states) have severely curtailed benefits for the treatment of mental illness, in far lesser amounts than needed by the chronically mentally ill. Their pharmaceutical needs -- psychoactive medication in most cases -- is expensive and uncovered."

While financial incentives continue to push hospitalization and congregate care, leaving deficiencies in the community system, the numbers of the mentally ill are seen as growing by many professionals. There is an almost Catch-22 situation at

work in the field. As underfunded community alternatives to hospitalization continue to be unable to handle the problems of the mentally ill, so are the state facilities that were originally supposed to wither after deinstitutionalization was seen as the new alternative. This is seen especially in the increase in short-term hospitalizations of young patients.

"Statistics have shown that only 10-30 percent of former hospital patients are employed at follow-up and that rehospitalization is high; 35-50 percent have been readmitted within one year after hospital discharge and 65-75 percent within five years." (54)

The so-called revolving door phenomena of frequent readmissions is especially frustrating to staff at many facilities, Senate staff found. These hospital employees said patients are frequently stabilized with medication and the hospital routine to the point where their psychiatric symptoms subside dramatically. Once released, however, many patients quickly "decompensate," fail to take medication, and once again enter an "acute" phase of their illness.

Returning to the hospital, they are met by an increasingly frustrated staff, especially direct-care staff, who are skeptical that the cycle can be broken.

"I'd like to see something like a habitual offenders law in the mental health code," said a direct-care aide in a Texas hospital. "Some sort of legal hold to make sure the patients comply with the rules and take their meds (medication)."

In Michigan, the mother of a 32-year-old man who had been hospitalized and released "many times," told Senate staff her son spent much of his time during discharges locked in his darkened bedroom. On two occasions, she said she was forced to call the police after her son became enraged, destroyed furniture, and threatened her. "I told him to take his medication, but he said he doesn't have to; he says he's got his rights from the mental health and they said he doesn't have to," she said.

A program director at a state hospital in Texas said that, too often, patients are discharged to themselves on strictly legal criteria. "Once you get a patient to the point where he's not a danger to himself or others, then they don't meet the hospital criteria, but that point is passed often long before there is any rehabilitation," he said.

One study noted that, "Even with the best possible outpatient care, many chronic psychiatric patients require admission, or readmission, for inpatient treatment. As federal and local fiscal cutbacks further overload already heavily burdened community support services, increasing numbers of patients and patients' families come to inpatient services requesting (or demanding) hospitalization for a patient who has never gotten well." (55)

In Colorado, Senate staff spoke with two of the four persons at the Ft. Logan Mental Health Center who are under contempt of court citations for refusing the order of a state judge to admit a court-committed individual.

The decision was a clinical one, the individuals said, and was made after a period of time when the high number of admissions of the facility had forced some patients to sleep on the floor.

Psychiatrist James Graves, formerly a consultant to the Public Health Service during the Kennedy Administration and described as one of the architects of deinstitutionalization, described the situation in the following manner: "Lots of people really thought we could end hospitalization, but nothing could be further from the truth. The chronically ill have suffered most. They've jammed up the community mental health services, but there aren't enough (local services) available." (56)

The lack of funding for community alternatives to hospitalization is but one of the jeopardies faced by those whose job it is to staff what is often the front lines of mental health care.

In Connecticut, Senate staff interviewed shelter operators in two cities who said their facilities were being jeopardized by bizarre or aggressive young individuals who disrupted the shelters with their behavior. One operator said his only option was to contact the police to transport the individual to a local hospital emergency room.

The Connecticut Hospital Association announced Jan. 21, 1985 it would lobby the Legislature to require state hospital admissions for patients legally certified by doctors. The association complained that patients often lingered for days in hospital emergency rooms waiting for open beds in state mental

institutions.

An association official, in a recent press interview, said psychiatric wards of general hospitals and state mental hospitals had occupancy rates of 90 percent and above. General hospital officials reported patients waiting up to 14 days in emergency rooms for admission to psychiatric inpatient care and a "standing room only" situation in one emergency room holding area. (57)

Dr. Randall Stith, director of the Aurora (Colo.) Community Mental Health Center and director of the Colorado Centers and Clinics Association told Senate staff two forces are at work keeping demand for services extremely high.

> "We just can't keep up with the sheer population growth, so that's one of the major reasons for the increase in demands for services. The other reason -- and it's one we're working with other mental health centers to try and figure out -- is that while the numbers are increasing for us proportionate to that rapid population growth, the severity is increasing of the client we do see and are coming in there more seriously disturbed and that's a different issue and we're not real sure of what the elements of that are."

Stith's questions about the nature of the special problems of these so-called young adult chronic patients are echoed elsewhere by psychiatric professionals. There is a sense in the psychiatric literature and among professionals interviewed by Senate staff that this new wave of the mentally ill, without afternatives in the mental health system, is already breaking

over the nation's state hospitals. "Today the 64 million babies born between 1946 and 1961 are between the ages of 21 and 36. They represent nearly one-third of the nation's population. Because of their overrepresentation in the population, the absolute number of young persons at risk for developing schizophrenia and, later, other chronic mental disorders is very substantial...the coming of age of children born after WW II is now having a marked impact on the psychiatric system." (58)

A social worker on a ward of a Texas state hospital said the newer patients have a longer period of time outside the mental health system to develop illness.

"We don't see patients in the hospital for a very long period of time anymore," she said. "These patients have character disorders, they look slick and streetwise and they frequently have medicated themselves with street drugs. The street is more forgiving, so we see them when they are sicker, but they aren't really chronic patients or passive or dependent."

A study of admissions to New York state adult psychiatric centers -- with 21,000 inpatients, the largest system in the nation -- showed "patients now being admitted are sicker, more hostile, and more difficult to treat."

The study concluded that "young people, especially young adult males, represent an increasingly larger proportion of the inpatients at state psychiatric centers. During the past five years young adult admissions to state centers have increased, as have their lengths of stay and the absolute number of young

adults hospitalized at any point in time...

"These observations have major significance, particularly because the probability of release decreases greatly as the length of stay increases, and the young patients have many years ahead of them. The dimensions of their impact on the state hospital census, together with their larger impact on the rest of the service system, underscore the growing challenge that this special group presents to the field as a whole." (59)

The clinical director of one Colorado facility said the new, young patients, in many cases, have been sheltered by their families. "The families of these patients are just burned out and the patients have burned all their other bridges," he said.

A study of 294 such young adults by one group of mental health clinicians included a profile similar in tone to many such statements by mental health professionals.

"The presenting disturbances of these young adults and their social and treatment needs are disconcertingly similar, for they spring from the problems all these patients have in common: their acute vulnerability to stress, their difficulty in making stable and supportive relationships, their inability to get and keep something good in their lives, and their repeated failures of judgment, which can be seen as an inability or refusal to learn from their experiences. These patients provoke an uncommon amount of frustration and distress, not only from their relatives and associates but also from their clinicians and case-workers. They confound our efforts to treat them by conventional means,

they evade yet repeatedly disturb our mental health programs, and they appear again and again in our psychiatric emergency services and police stations. Some, though not all, sojourn briefly in our psychiatric hospitals, where their names are likely to be well known, where they consume disproportionate quantities of staff time, where, recalcitrant children, they create more than their share of consternation, where they are the subject of multiple case presentations and interagency treatment planning conferences-only to be discharged back into lives that often prove once again untenable. These patients rarely reward our efforts with improvement. Instead they become, individually and collectively, our albatross. They are functioning persons only in a marginal sense; they manage their lives tenuously at best and disastrously at worst. They are discharged when their most acute symptoms have abated, but typically their remissions are incomplete." (60)

More importantly to state hospital direct-care workers, with whom psychiatric patients spend all but a fraction of their day, is the ever-present threat of violence by these younger patients.

"Many of these patients are characterized by assaultive behavior, severe overt psychopathology, lack of internal controls, reluctance to take psychotropic medications, an inability to adjust to open settings, problems with drugs and alcohol in addition to their psychoses, and, in some cases, self-destructive behavior. They often require highly structured community settings such as locked skilled nursing facilities of extended stays in state hospitals.

"Assessing the need for external control and structure is extremely important. When an attempt is made to manage such patients in less structured community settings, as in community mental health programs, these patients, though relatively few in numbers, tend to take up an inordinate share of the time and effort of mental health professionals. Further, although acting out defiantly, rebelliously, and violently may be an attempt to achieve independence and individuation, the community may not be able to tolerate the actions of these patients who do not demonstrate sufficient self control." (61)

At Dorothea Dix Hospital in Raleigh, N.C., a facility named for the famed 19th century reformer who encouraged construction of state hospitals, 49 percent of the 1981 admissions were patients in the age group 18-34. Of that group, the chief of the hospital's psychiatric services said, "They are totally difficult to deal with. They have the most provocative ways; most challenging ways. And, indeed, they release in most of us the most murky kinds of feelings, which are counter-productive." (62)

The frequent inability of staff to adequately control volatile hospital situations related to Senate staff by hospital employees, patients and advocates, is especially troubling in light of the predictions being made by mental health professionals.

One such prediction is that populations in mental hospitals could rise appreciably in the future.

Dr. Herzl R. Spiro of Vanderbilt University has established

a set of variables that influence the numbers of patients likely to use state mental hospitals in the future. In a 1982 article, Spiro said "several of these variables have shifted significantly to increase the size of this population."

Citing information from a variety of research sources, Spiro concludes that "a renewed state hospital system is much needed to meet the anticipated increase in chronic, severely mentally ill patients."

The variables he cites include the expected increase in major psychiatric disorders as the population increases and the so-called baby-boom generation reaches the age of greatest risk for the disorders. Along with this increase is the decrease in less restrictive elements of the mental health system, such as emergency and outreach programs. The absence of these elements "may delay entry of some patients into the care system until their deleterious social complications are thoroughly established."

Spiro further cites data that shows rates of state hospital utilization rise during periods of economic hardship and unemployment. Also rising, he said, is the level of violence and the prospects that society will turn to secure public facilities as the answer to psychiatric patients exhibiting these behaviors. "Violent behavior, repeated substance abuse, and acting-out behaviors are more difficult to handle in community settings, nursing homes and general hospitals. Thus violent patients are likely to be transferred to state hospitals, often after being refused readmission to private facilities and general hospitals."

An evolving societal attitude, coupled with a severe shortage of alternatives, will place extra pressures on minority populations of the mentally ill, Spiro's research suggests.

> "The atrocious conditions in state asylums during the 19th century were largely produced by waves of European immigrants who generally resorted to public hospitals for treatment. Today the groups most frequently hospitalized in government institutions are blacks and Hispanics. High birth rates among both of these groups have produced an 'internal migration', resulting in demands for state hospital beds resembling those produced by the 19th century European immigrants...Liberalization of commitment laws and toleration of deviance probably reached its peak during the past 15 years. As the pendulum swings away from the extremely restrictive commitment laws and as some of the civil rights emphasis on personal freedom gives way to increasing emphasis on social control and order, patients are again likely to be sent to government institutions." (63)

In Texas, a state where the population jumped 27 percent between the 1970 and 1980 census, a special study panel appointed by the Legislature reported in January 1985 that the number of patients in state hospitals will jump 34 percent in the next five years barring major improvements in mental health services. Among the panel's recommendations were hundreds of additional community beds, a system of community case managers for discharged patients and new legislative authority to license what are often squalid boarding homes for the mentally ill. (64)

Last September, a pair of Harvard psychiatrists recommended the state of Massachusetts spend an estimated $25 million to construct six new mental health facilities to house approximately 1,000 patients deemed inappropriate for community care. (65)

If adopted, the proposal would mean an almost 50 percent increase in the state's institutionalized mentally ill population.

As an illustration of the changing nature of discussion on the issue of the state's role in mental hospitalization, a 33-member blue ribbon panel in Massachusetts recommended in 1981 that all five of the state's mental hospitals be closed within five years. Nearly half of the panel's members signed an alternative position paper questioning the ability of community resources to handle the discharged patients. (66)

Reports of innovative attempts at stabilizing young patients during an acute or crisis stage of their illness as a way of preventing the need for long-term hospital care have not been encouraging.

The Hutchings Psychiatric Center in Syracuse, N.Y. was constructed in the early 1970s, "designed to embrace the community mental health ideology and focus new programs on relatively young patients who were entering the mental health system for the first time."

The facility staff, "Imbued with optimism...intended not only to treat serious mental disorder but to prevent the scars of

chronicity so widely associated with long-term hospital care." Despite these objectives, the facility faced increasing demands for service including a 20 percent increase in 1980 alone.

The reason suggested as "most responsible for the current bed crisis concerns the build-up of new long-stay patients. This is particularly true to those young adults who are difficult to place in community settings because of a history of arson or assault, or a diagnosis of mental retardation, or because they are being held under criminal proceeding. It is also true of older patients who need skilled nursing, which is often difficult to arrange, or other health-related care."

An analysis suggests "the problems and experiences of the Hutchings staff may reflect a trend that will probably influence most of the nation's mental health service providers." (67)

Such a trend may already be established. Figures compiled by the National Institute of Mental Health show that in 1978, for the first time since the 1950s, admissions to state mental hospital inpatient units began exceeding discharges. The total number of inpatients in these facilities has continued to decline slightly only because the death rate of patients continues to exceed net new admissions.

"In the heyday of deinstitutionalization it was thought that most of the chronically mentally ill who were warehoused in state mental hospitals would be discharged, and that those who remained would gradually die, making the back ward a historical curiousity. A concurrent replacement of that population,

however, is preventing that from occurring. The new and intermediate long-stay groups illustrate that the process of institutionalization, as determined by length of stay, goes on.

> "...the marked slowing of the trend toward decreasing resident population marks yet another turning point for these institutions. Action taken by federal and state authorities at this turning point will possibly have more leverage than at other times, and could set the course of events for a long time into the future." (68)

Institutionalization and the Mentally Retarded

The trend for mentally retarded and developmentally disabled persons over the last 18 years has been one of gradual deinstitutionalization. When institutionalization was at its peak in 1967, 130 out of every 100,000 Americans were institutionalized mentally retarded persons. In 1982, 106 out of every 100,000 Americans were institutional mentally retarded persons. The rate of institutionalization is 18 percent lower in 1982 than it was in 1967.

The ICF/MR program reflects this trend to some extent. ICF/MR residents in facilities of 15 beds or less have grown from 1,725 in 1977 to 9,714 residents in 1982. However, as of 1982 these residents still represented only 6.8 percent of all ICF/MR residents. The other 130,970 ICF/MR residents remain in facilities of 15 beds or more, with 93,171 residing in institutions of 301 beds or more. The certified beds in these large institutions have continued to increase over the last 5 years (from 106,917 in 1977 to 140,684 in 1982). The ICF/MR program remains predominantly a program of institutionalization.

The ICF/MR program needs to be altered to provide an incentive to states to serve mentally retarded persons in the least restrictive environment. Ten years of experience with PL 94-142 has demonstrated the benefits of mainstreaming mentally retarded and developmentally disabled persons rather than segregating them. Where institutions were once thought to be the "state of the art" in care and treatment for mentally retarded/

developmentally disabled persons, today's knowledge tells us that a maximally mainstreamed setting is the "state of the art."

Safeguards against abuse and neglect, as well as the provision of active treatment need to be increased. Simply increasing staff, no matter what the residential setting, is not the solution. At one Connecticut institution visited by Senate staff, the certified buildings have twice the staffing ratio of the non-certified buildings. However, according to the superintendent of that facility, staff in certified buildings spend twice as much time doing paperwork as staff in non-certified buildings. Adequate staffing is essential, however staff must be trained to provide active treatment as their main job function. Increased technical assistance (such as that to be provided by the 12 new Developmental Disabilities Specialists HHS was directed by Congress to hire last year) is essential.

The deinstitutionalization of mentally retarded and other developmentally disabled persons has slowly begun. In order for this gradual shift away from institutions to community settings to be successful, reforms in federal policy are imperative. Incentives to provide adequate community settings need to be established. Mechanisms for monitoring care and services in community settings are critical in order to prevent the problems of abuse and neglect and lack of active treatment from following mentally retarded people from the institution into the community.

Mental Health Systems and the Federal Government

There is little new in revelations of substandard care and violence endured by mental patients in state facilities. Accounts in books, print and broadcast journalism and motion pictures have affirmed a widespread view in society that state mental hospitals are the lowest rung on the mental health care ladder and often, true "snake pits."

To a great extent, concern about care of the mentally disabled has been cyclical, sparked by rounds of publicity and indignation. Although these accounts are repetitious and frustrating to reformers, such stories about the plight of the severely mentally disabled through the decades move succeeding, evolving topics to the top of the public agenda in the field.

Social reform movements of the early 19th century brought to the fore the concept of "moral treatment," described in one account as the "belief that man could be perfected by manipulating his social and physical environment." (69) Construction of such facilities as the Friends Asylum in Pennsylvania and the Hartford Retreat in Connecticut around 1820 for "paying" patients led to concern for poorer patients who found a champion in Dorothea Lynde Dix. In the 1840's, Dix lobbied for the construction of state mental hospitals across the United States.

The resulting mix of public and private facilities led to a dual system of care as local poorhouses and even jails were able to transfer the financial burdens of care for chronic mental

patients to the next level of government.

"Private sector facilities tended to specialize in providing treatment to wealthier, quiet, primarily voluntary patients, while the state asylums were left to provide long-term custodial care to poor, disturbed, involuntary patients. As the care system evolved over the next century, a two-class system emerged and became firmly entrenched. (State institutions') central purpose were defined by state legislatures in terms of custodial care and community protection; treatment was of secondary importance. Emphasis was placed on the custody of the largest number of patients at the lowest possible cost." (70)

In the first half of the 20th century, the population in state mental hospitals rose from some 150,000 to 512,000, a 240 percent increase and nearly twice the nation's rate of growth. In the following 25-30 years, the population shifts at the facilities was similarly dramatic. Between 1955 when the hospitals' population peaked at 559,000, and 1980, the census dropped by some 420,000 patients, a 75 percent decline. Also similar was the mix of public outcry and financial incentives that fueled the shifts.

"Deinstitutionalization policy took shape in response to civil libertarian litigation over the state hospital commitment process, the Medicare-Medicaid amendments to the Social Security Act of 1965, and the fiscal crises that enveloped the states in the early 1970s. Similar to the state care acts of the late 19th and early 20th centuries, the Medicare-Medicaid amendments allowed for buck-passing from one governmental budget to

another--in this case from the states to the federal level. Within a short period of time, these fiscal and legal incentives led to the discharge of hundreds of thousands of mental patients from the state mental hospitals. CMHCs (Community Mental Health Centers) were almost totally unprepared or unwilling, or both to shoulder the responsibility for this chronic population." (71)

This shift of responsibility to the federal government was a move sought by reformers. A congressionally-mandated study by the Joint Commission on Mental Illness and Health, reported in 1961 after a five-year investigation that community mental health care was "a main line of defense in reducing the need of many persons with major mental illness for prolonged or repeated hospitalization." (72)

Certain chronic patients, the report said, would be kept in large state institutions along with victims of many chronic diseases, but most such facilities would be closed in favor of outpatient community care or psychiatric inpatient care in designated psychiatric wards of general hospitals. Two years later in October 1963, the passage of the Mental Retardation Facilities and Community Mental Health Centers Construction Act P.L. 88-164, threw the weight of Washington behind community controlled centers separate from state hospitals. As a result of the new policy, President John F. Kennedy told Congress, "reliance on the cold mercy of custodial isolation will be supplanted by the open warmth of community concern."

The legislation provided for the allotment of federal funds to the states for construction of community-based mental health

centers. A state's allotment was based on population, extent of facility need, and financial need. Each state was required to develop a comprehensive mental health plan along with a list of priorities. States were also required to provide assurances that the services of centers would be available to all and that a reasonable amount of care would be provided to indigent persons.

The Community Mental Health Centers (CMHC) program was amended and extended several times. Between 1963 and 1980, CHMC program provided funding for 763 centers.

During the period, a significant change in the pattern of treatment of mental illness took place. In 1955, three out of four persons treated for mental disorders received treatment as inpatients. By 1980, three out of four persons receiving mental health care were treated on an outpatient basis. Large mental hospitals, for the most part, became places to provide long-term care for those with chronic mental illness, and were to serve as back-up facilities for community-based care, as well as for short-term hospitalization in periods of crisis.

As successful as the CMHC program had been in supporting the development of community facilities for mental health care, it had also become clear by the mid-1970s to Congress, the executive branch, and the mental health community that the program was failing to provide adequate mental health care to certain groups with special needs, such as chronically mentally ill persons, severely disturbed children and adolescents, and elderly persons, among others. Community mental health services had become located predominantly in middle-class areas, to the detriment of

those living in rural areas, small towns, and the poorer sections of the nation's cities who were in need of mental health care, especially the chronically mentally ill who would have been hospitalized if not for deinstitutionalization.

Dr. M. Brewster Smith, a University of California psychologist and former vice president of the Joint Commission, said the panel's recommendation for this new national policy was based on "the sort of overselling that happens in almost every interchange between science and government...Extravagant claims were made for the benefits of shifting from state hospitals to community clinics. The professional community made mistakes and was overly optimistic, but the political community wanted to save money." (73)

Former commission staff director Jack R. Ewalt said the 1963 legislation resulted in states ceding most mental health responsibility to the federal government. "The result was like proposing a plan to build a new airplane and ending up only with a wing and a tail. Congress and the state governments didn't buy the whole program of centers, plus adequate staffing, plus long-term financial supports." (74)

The point has been made that in fact, the creation of community mental health centers as the successor to custodial care in institutions "exacerbated the plight of the chronic patient." First although construction of the centers encouraged deinstitutionalization, it also encouraged "previously untreated individuals" to seek mental health services, "largely ignoring the populations traditionally served by the state mental

hospitals."

> "The problem for CMHCs was compounded by two additional factors... the concept of federal 'seed money;' with federal contributions decreasing annually, often meant that centers had to abandon poorer patients with a pattern of high service utilization (such as chronic patients) in favor of insured patients who might respond to brief interventions. Second, CMHC funding was through a federal-to-local community grant mechanism that avoided state involvement. This attempt to circumvent state mental health agencies in order to avoid control of CMHCs by 'institution-minded bureaucrats' also meant that the depopulation of state mental hospitals would proceed without coordination with the new centers." (75)

In 1977, President Jimmy Carter established a Commission on Mental Health to review the mental health needs of the nation and make recommendations to meet these needs. The Commission's report in 1978, found, among other things, that the CMHC Act had accomplished a great deal, but it also found that substantial problems persisted. The report noted that certain populations were underserved by the program, and that there were shortages of trained mental health personnel in certain areas. The Commission report made recommendations in eight broad areas: community support, services, insurance, personnel, basic rights, research, prevention and public understanding. In making 42 specific recommendations, with many subparts, on safeguarding rights, the Commission's task panel on legal and ethical issues stated that "the panel is also keenly aware that even the best intentioned

efforts to deliver services to mentally handicapped persons have historically resulted in well documented circumstances of exploitation and abuse." The panel concluded that "perhaps the most important point that (we wish) to convey to the Commission is the importance of building a strong patients' rights and consumers' perspective into any reforms in the services system." (76)

To further stress this point in its report to the Commission, the task panel recommended initiatives be taken to promote legal advocacy.

Taking the panel's view, the Commission recommended the establishment of a legal advocacy system to protect the rights of mentally disabled persons receiving services. Even though the task panel had noted that there were many different and valuable kinds of advocacy systems to secure services and protection of clients rights, it stressed that its focus was on legal advocacy. Under the panel's definition, legal advocacy "... is directed toward establishing and enforcing the legal rights of mentally handicapped persons...(and) includes both consumer-oriented efforts to protect the liberty and other fundamental rights of mentally handicapped persons." (77)

The panel's recommendation to the Commission endorsed the creation of federal and/or state mechanisms to develop advocacy systems. It suggested the requirements for any advocacy system must be: "(1) able to respond to the legal needs of mentally disabled persons and (2) independent of providers of mental health and developmental disability services. An essential

feature of such advocacy systems should be their effort to provide a continuity of legal services to such persons at all stages of their contact with the mental health system. Such advocacy systems should provide services at involuntary commitment proceedings and to institutionalized persons of all ages, as well as to community residents, in matters involving institutionalization (commitment, release, treatment issues), the fact of present or former institutionalization (availability of economic benefits, aftercare, denial of civil rights, employment, education issues), and other matters related to the existence--or perceived existence--of a handicap (domestic relations, contracts, wills, tenancy issues). In addition to attorneys (an "indispensable element in seeking and securing many types of remedies"), the advocacy system should be staffed by persons trained as "mental health professionals" (e.g., social workers and psychologists who provide advocacy services), by lay advocates, and by present and former recipients of mental health services, so as to provide a full-time staff with the necessary academic training and practical experience to provide comprehensive advocacy services for its clientele." (78)

In addition to providing legal counsel, the Commission also recommended a bill of rights for the mentally disabled, which articulated the following general principles:

- The right to treatment and habilitation and to protection from harm for all involuntarily confined mentally and developmentally disabled patients;
- The right to treatment in the least restrictive setting;

- The right to refuse treatment, with attention to the circumstances and procedures under which the right may be qualified;
- The right to due process when community placement is considered. (79)

In 1980, the Congress enacted the Mental Health Systems Act, P.L. 96-368 drawing heavily from the recommendations of the President's Commission.

In this Act Congress sought to integrate the state and federal roles in promoting community-based mental health care. Congress recognized that just as there was a need to integrate the mental health services between state and local governments, there was a need to provide a uniform system to protect patient rights in the health care delivery system. The Senate Committee on Labor and Human Resources, in its report on the bill which eventually became P.L. 96-368, established a bill of rights for the mentally ill and provided a system to protect those rights. (80) As reported by the Senate committee, the original bill intended to establish "a basic, though not comprehensive, set of rights for the purpose of assuring a greater measure of uniformity in their interpretation and implementation" among the states.

In setting forth these rights the committee report stated that it had carefully reviewed the state statutes and judicial rulings that had established many rights, "in varying terminology." But the rights found among jurisdictions "were highly inconsistent and often ambiguous." (81) The committee

tried to clarify and consolidate a set of principles under the act in a bill of rights section, including the following:

- The right to appropriate treatment and related services in a setting which is most supportive and least restrictive of a person's liberty.
- The right to an individualized, written treatment or service plan.
- The right, consistent with one's capabilities, to participate in and receive a reasonable explanation of the care and treatment process.
- The right not to receive treatment without informed, voluntary, written consent, except in a documented emergency or as permitted under applicable law for someone who has been civilly committed.
- The right not to participate in experimentation in the absence of informed, voluntary, written consent.
- The right to be free from restraint or seclusion except in an emergency situation pursuant to a contemporaneous written order by a responsible mental health professional.
- The right to a humane treatment environment that affords reasonable protection from harm and appropriate privacy.
- The right to confidentiality of personal records.
- The right to have access to personal mental health records and have a lawyer or legal representative have reasonable access to records if the patient provides written authorization.
- The right to private conversations, reasonable access to telephones and mail, and to visitation during regular

visiting hours.

- The right to timely and meaningful information about one's rights at the time of and after admission.
- The right to assert grievances with regard to the infringement of rights and to have a fair, timely and impartial grievance procedure provided.
- The right of access to, including private communications with, any available rights protection service or qualified advocate.
- The right to exercise other rights without reprisal, including denial of appropriate treatment.
- The right to referral as appropriate to other providers of mental health services upon discharge.
- The rights described in this section should be in addition to, and not in derogation of, any other statutory or constitutional rights.
- The right to confidentiality of and access to records continues following one's discharge.
- No otherwise eligible person should be denied admission to a program or facility as a reprisal for exercising any of these rights. A program or facility is not required to admit a person who has previously refused to accept treatment, may discharge persons whose refusal of treatment prevents treatment, and need not treat persons admitted solely for evaluative purposes.
- The patient has a right that his attorney or legal representative have reasonable access to the patient/client, the facility at which the patient resides and, with

written authorization, the patient's medical and service records.

- Each program or facility should post the rights available to the patients.
- A patient who is incompetent may exercise rights through a court-appointed representative or legal guardian, chosen so as to avoid conflicts of interest.

Along with court decisions and state statutes, the Senate committee, in crafting the rights provisions of S. 1177, also took notice of other federal statutes, particularly the Developmental Disabilities Assistance and Bill of Rights Act.

Provisions of the MHSA were modeled after the Developmental Disabilities Act, which established a bill of rights for persons with developmental disabilities. Focusing on the conditions in institutions where disabled persons reside, the rights articulated in the Developmental Disabilities Act provide guidance for the service providers and were to be considered in addition to any constitutional or other rights afforded to all citizens. To assure that these rights were protected, the Act also required the states, in order to receive funding, to establish systems to protect and advocate the rights of persons with developmental disabilities.

Prior to 1978, the term developmental disability was defined to include mental retardation, cerebral palsy, epilepsy, and autism. The 1978 amendments to the Act, changed the definition to include people with specific major functional difficulties. Such difficulties include impaired capacity to care for one's

daily personal needs, impaired capacity to understand and express language, impaired learning ability, and impaired independent mobility. While it was acknowledged that the mentally ill fit the new definition and could be covered by the Protection and Advocacy offices established by the states pursuant to the Developmental Disabilities Act, the focus of the P&A's of many states continues to be on services to mentally retarded and other developmentally disabled persons. Few state Protection and Advocacy Offices established pursuant to the Developmental Disabilities Act also serve patients in psychiatric hospitals.

With the Mental Health Systems Act, Congress attempted to meet the need for advocacy for the mentally ill. The bill provided funding for a grants program for protection and advocacy, similar to the Developmental Disabilities Act.

The design and funding mechanism for this program were different than under the Developmental Disabilities Act, but noting that some states may have successful offices and that existing P&A's may wish to expand and apply for grants for the mentally ill, the bill did not mandate a uniform design for the advocacy program. Certain criteria were established for eligibility for states. One criteria was that the advocacy office be independent of the service provider in the state. Similarly the bill required that the grant review process be separate and independent from any part of the Department of Health and Human Services involved in funding mental health service providers.

The committee report strongly urged that the Legal Services

Corporation, which had operated several experimental advocacy projects, be involved with HHS in reviewing requests for funding, and it stated the committee's intention that the program also be coordinated with Legal Services Corporation programs. The intent was to have a separate entity from service providers receiving requests for rights protection.

The bill as reported out of committee further provided that patients of facilities covered by the Act would be entitled to the assistance of counsel in bringing suit to vindicate violations of the bill of rights. Finally, in order to receive any funding for assistance under the Act, states were mandated to establish advocacy programs and the Secretary of Health and Human Services was given authority to discontinue funding for mental health centers if a state failed to enact necessary provisions establishing the basic rights delineated under the bill of rights section of the Act.

During Senate floor debate on S. 1177, Senator Robert Morgan of North Carolina strongly objected to the requirement that states adopt the bill of rights. He argued that states were as equally concerned as the federal government with preserving the rights of mental patients. Since the states had the primary responsibility for the care of patients, establishment of rights for patients was not a proper role of the Congress. Furthermore, it was asserted by other senators that several states had patient rights laws which were similar to those articulated in the MHSA. The claim was made that as many as 35 states had similar statutory provisions. (82)

Thus, an amendment to the bill was offered and accepted, changing the requirement that states adopt the bill of rights to a "sense of the Congress," which recommended that the states "review and revise" their statutes to conform with the bill of rights provision. Also, the section of the bill which gave individual patients the right to bring lawsuits to redress violations of the bill of rights was deleted.

In 1982, a report on a survey of states done by Martha Lyons, Martin Levine and Jack Susman concluded that the assumption by some senators that most states had similar laws protecting mental patients' rights, was "essentially in error." They found that both the number of states, 35, and the scope of the rights recognized by state statutes were inflated. While they found some state statutes recognized rights not included in the Mental Health Systems Act, they also concluded that to meet the standards recommended by Congress many states' laws would have to be changed significantly. (83)

The programs and authorities of the Mental Health Systems Act were scheduled to take effect in fiscal year 1982. The Reagan Administration, however, proposed in 1981, and the Congress enacted, a change in federal support for mental health services from the project grant approach of the Community Mental Health Centers Act and the Mental Health Systems Act to the Alcohol, Drug Abuse, and Mental Health Services (ADAMHS) block grant approach. The Omnibus Budget Reconciliation Act of 1981, P.L. 97-35, among other things, repealed most of the CMHC Act and the Mental Health Systems Act, including the newly authorized

categorical program of protection and advocacy grants. The suggested bill of rights remained in the law, but with the repeal of the protection and advocacy grants, there is currently no federally-supported protection of those rights.

In June 1984, the General Accounting Office reported that federal support of the services comprising the ADAMHS block grant had declined 21 percent from $541 million to $428 million between 1981 and 1982. In fiscal year 1984, the block grant was increased nine percent to $462 million, and to $490 million in fiscal year 1985.

The Governor's Select Commission on the Future of the State-Local Mental Health System, a New York panel, said in its August 1984 draft report that federal support has declined even more substantially in recent times: "The recent economic recession resulted in federal policy that curtailed welfare expenditures. Not only has direct financial support in the Alcohol, Drug Abuse and Mental Health block grant been sharply cut, but in its SSI/SSD and housing policy, the Reagan Administration has withdrawn fiscal support from the states and localities. The federal government has placed the burden of care for the long-term mentally ill on the states. The pressure on the states has been enormous." (84)

Certain experimental protection and advocacy projects for the mentally ill were funded within the National Institute of Mental Health (NIMH) under their research authority in the late 1970s. In all, 28 demonstration projects were funded. An in-depth evaluation of 10 of those projects, conducted after they

had been in operation for two years, came to the following conclusion: "...the general theme that emerges from this two-year undertaking is that advocacy services can and should be a permanent facet of any comprehensive mental health system." (85) Nevertheless, the Administration has not proposed, nor has Congress enacted, any protection and advocacy legislation subsequent to the repeal of the Mental Health Systems Act. Neither have any additional advocacy projects been funded under the research authority of NIMH.

In 1977, NIMH initiated the Community Support Program (CSP), to work with states and localities to improve opportunities and services for adults with chronic mental illness. According to NIMH, the program focuses specifically on those adults who are inappropriately institutionalized in hospitals or nursing homes, and the large number of such persons who are living outside of hospitals without adequate housing or life-support services. NIMH estimates there are between 1.7 and 2.4 million such persons at the present time.

The 1984 Alcohol, Drug Abuse and Mental Health Amendments authorize the Secretary of the Department of Health and Human Services to make grants to states and political subdivisions, and private nonprofit agencies for mental health services demonstration projects for the planning, coordination, and improvement of community services for chronically mentally ill individuals, seriously mentally disturbed children, and elderly individuals, and for research concerning such services. The Community Support Program has awarded modest grants to State

mental health agencies to encourage placing greater priority on the needs of this population and to mobilize States and communities to improve opportunities for the chronically mentally ill, such as vocational rehabilitation and subsidized housing.

Considerable attention by commentators has been given to the necessity for advocacy systems to protect the rights of the mentally disabled. In their book entitled Legal Rights and Mental Health Care Herr, Avons and Wallace wrote:

> "Describing the attributes of mental-health advocacy can be controversial, especially given the great variety of types of advocacy and advocates who labor at this work. Mental-health advocates may be lawyers or laypersons; they may be well-trained recent college graduates, experienced community members, ex-patients, or trained of other professions. The training and supervision available to them and the forums in which they can advocate on their clients' behalf vary enormously from state to state and from advocacy project to advocacy project. In terms of personal commitment, aggressiveness, craftsmanship, and personality, advocates provide a spectrum no less broad than clinicians. Yet through all the differences in advocacy there are fundamental principles that must be maintained if advocacy is to be its own ethics and useful to its clients." (86)

As outgrowths of the attention to the structure, design and needs of patient advocacy offices several studies of existing advocacy projects around the country were done in 1980-1981. One evaluation of advocacy models sets out the following description

of the four necessary elements of an ideal mental health advocacy system:

> "First, it should include a rights protection mechanism within the service delivery system designed to prevent violations of the rights of institutionalized clients, to operate a grievance system, and to monitor the ongoing delivery of mental health services, thus guaranteeing that remedial action will follow rights violations. Second, a comprehensive mental health advocacy system should include a legal advocacy mechanism independent of the service delivery system and capable of taking legal action against it in cases beyond the competence of the internal agency. Third, it should include a citizen advocacy mechanism in order to promote constructive relationships between mentally disabled people and members of the general public. Finally, a comprehensive mental health advocacy system should have as its ultimate objective training mentally ill and mentally retarded individuals to advocate on their own behalf whenever feasible, thereby minimizing the risk of paternalism in advocacy efforts and equipping mentally handicapped persons to be autonomous and self-reliant citizens to the furthest extent possible." (87)

The Courts and Protection of Patients' Rights

Introduction

In the last 20 years, there has been tremendous growth and expansion in the civil rights of the mentally disabled in state facilities. Clearly, gone are the days when patients left their rights at the door. Though basic rights have emerged from federal and state court decisions, statutes and administrative regulations, the law is still unsettled and continues to be redefined and refined. Just as the substantive rights recognized from state to state and among federal court jurisdictions vary, the systems to enforce those rights and the effectiveness of those systems are also diverse.

Advocacy of patients' rights in the courts is generally seen as a major contributing factor in deinstitutionalization. These advocates have also brought about significant changes in institutional conditions and the quality of care provided patients. Despite the progress in terms of judicial and legislative reforms, many of the deplorable and substandard conditions in public institutions still exist. With increased attention on the homeless mentally ill and some proposals for the relaxation of civil commitment standards, conditions in public hospitals will deserve more attention.

Judicial Decisions on Constitutional Rights of Mentally Disabled

Civil Commitment

The criteria and procedures on involuntary admission of an individual to a public mental institution is set by state statute. With the confinement to an institution being the most severe restriction to an individual's liberty and freedom of choice, constitutional challenges and legal reforms in state commitment statutes have often been the basis for broad reforms and recognition of rights of mentally disabled individuals. Legal theories from these cases and revisions of statutes have provided the foundation for other challenges to institutional conditions. Since the commitment process governs the flow of patients in and out of the hospital, it continues to be a hot topic of debate among mental health professionals, particularly between psychiatrists and legal advocates. It is in the context of commitment hearings that the tension and debate between the medical and legal professions continues.

The power of the state to involuntarily confine an individual to an institution derives from either its police power or its power as parens patriae (parent of the country).

Under its police power, the state is granted the authority to proscribe individual behavior in order to protect the public health, safety and welfare. In criminal cases the police power, however, is not unlimited; even someone charged with a crime is protected by procedural safeguards before they can be deprived of

liberty. Under the police power, the state may involuntarily admit a mentally ill individual to a state mental institution if that person is dangerous to himself or others. In civil commitment, the police power is used when the purpose of commitment is to further a societal interest, such as protection for the public, rather than the interest of the person committed. But prior to some of the constitutional cases challenging commitment statutes, procedural protections provided prisoners were not applied to the civil commitment process. The second basis of commitment statutes served as the rationale.

Under the parens patriae power, the state can admit a person to a state mental institution, against his will, if the person is mentally ill and is in need of care and treatment. The rationale for the use of parens patriae was often viewed as a humanitarian one -- to protect those persons who are unable to protect themselves.

Two leading cases that established constitutional protections in the commitment process were Lessard v. Schmidt 349 E. Supp. 1078 (1972) and O'Connor v. Donaldson, 422 U.S. 563 (1975). The Lessard case provides an example of how easy it was to commit someone before state statutes were changed.

In this case, Alberta Lessard was picked up by police at her home in West Allis, Wisconsin and taken to a mental health center. After the police filed a petition requesting that Lessard be evaluated, she was detained at the center on an emergency basis. A judge issued two orders without her being present at the hearing and authorized her detention for 20 days.

After the initial emergency confinement, a series of evaluations took place, which were followed by 30 days additional confinement. Under Wisconsin statute it was possible for her to be involuntarily confined for a period of 145 days without benefit of a hearing. Lessard sued state officials alleging the Wisconsin statute violated her rights to due process including the denial of adequate notice of a hearing; the deprivation of her right to counsel; the violation of the privilege against self-incrimination and denial of speedy hearing.

The district court held that the Wisconsin civil commitment procedures did not provide adequate due process rights to those who were committed and ordered that numerous safeguards, including those claimed by Lessard, be instituted. The decision established at a minimum the following rights prior to involuntary commitment:

(1) notice of and time to prepare for proceedings;
(2) representation at the hearing;
(3) the right to be present at the hearing;
(4) a clear statement of the reasons for the commitment and
(5) a right to judicial review of and appeal of the commitment decision.

The second important case focusing on commitment standards was decided by the Supreme Court in O'Connor v. Donaldson. This case involved a challenge to the basis of a state statute on involuntary commitment.

Kenneth Donaldson had been involuntarily committed to

Florida State Hospital by his father. The father asserted that his son suffered from delusions. Under Florida statute, Donaldson was committed for care, maintenance and treatment. He had been confined for approximately 15 years and had repeatedly requested release to the care of friends who were willing to ensure his safety. His requests were always denied. He filed a petition in district court requesting his release and claiming that his constitutional right to treatment was violated because he had received none.

Evidence was presented at trial that Donaldson had never been dangerous to himself or others during this confinement (nor at any time during his life) and, if mentally ill, he had not received treatment. Members of the hospital staff testified that for substantial periods of time, Donaldson was kept in a large room with 60 other mental patients, many of whom were criminally committed.

The statute which authorized Donaldson's confinement, which had been repealed by the time of the Supreme Court's opinion, had allowed for indefinite custodial confinement of the mentally ill, even if they were not treated and their release would not be harmful.

The district court ruled in favor of Donaldson and the decision was appealed. The Court of Appeals affirmed the lower court's ruling and held that Donaldson had a constitutional right to treatment. The court noted that when the rationale for confinement is that the patient is in need of treatment, as in Donaldson's case, the Constitution requires that minimally

adequate treatment be provided.

Although the Supreme Court vacated the right to treatment holding of the Court of Appeals, it held, however, that a state cannot constitutionally confine a non-dangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends.

Since the decisions in these cases, state statutes have been reformed to meet the procedural requirements of Lessard and the substantive basis for commitment have been changed to meet O'Connor.

Actually, some state statutory reform predated these decisions. One such state was California, where in 1968, the Landerman-Petris-Short (LPS) statute revised the state's standards for commitment.

Under LPS, individuals may be involuntarily committed if they are mentally ill and are:

(1) dangerous to themselves
(2) dangerous to others or
(3) gravely disabled.

Lawyers and psychiatrists have long debated whether an involuntarily committed person should be committed under parens patriae power or the police power. The real reason behind involuntary commitment, the legal argument suggests, is the protection of society under the guise that the patient, although mentally ill, poses a dangerous threat. Adherents to the medical

argument, on the other hand, believe that involuntarily committed patients are admitted because they are unable to care for themselves and therefore commitment is necessary. This tension between the professions can be seen in the context of the American Psychiatric Association's proposed model law to reform commitment statutes.

Dr. Allan A. Stone, former president of the American Psychiatric Association and chief draftsman of the model law, states that the model law draws from both medical and legal concerns and transcends both by placing the interests of the patient first. With respect to parens patriae commitment several states use the concept of "in need of care and treatment" as a standard for involuntary civil commitment.

Although the trend in recent years is to specifically require dangerousness for commitment or to require a likelihood of serious physical harm, the requirement of "in need of care" is still used. Two-thirds of the states permit the involuntary confinement of a person who is "gravely disabled," usually meaning that the person is unable, because of severe illness, to meet his basic needs for food, clothing, shelter and medical care.

Under the model law, parens patriae commitment would require that the patient suffer from a severe mental disorder, lack the capacity to make decisions concerning treatment, be treatable and likely to harm himself or others. Such persons would include those who are likely to suffer substantial mental or physical deterioration, as well as those who are dangerous or unable to

care for themselves. The objective of this type of commitment is to allow commitment of many severely mentally ill persons ignored by current commitment laws, especially the homeless mentally ill.

With respect to the police power of a state generally, the concept of dangerousness to self or others is usually a standard for involuntary civil commitment in current law only if the dangerousness is caused by a person's mental illness.

The term "dangerousness" is not interpreted uniformly by the states, however.

Some states require an overt act such as an attempt or threat to do substantial harm; some require harm to property as grounds for commitment and others rely on a medical opinion that the individual is likely to do harm.

Courts normally rely heavily on testimony of psychiatrists and other mental health professionals to predict the potential dangerousness of an individual given that person's history.

The American Psychiatric Association believes that a psychiatrist cannot predict potential dangerousness of a person and thus confinement should not be based on that prediction. In the adverserial setting of commitment hearings, this issue has been problematic for psychiatrists who have felt patients needing treatment were not committed.

Under the model law, police power commitment would require a severe mental disorder, clear and convincing proof of likely dangerous behavior, lack of capacity to make decisions concerning

treatment, and evidence that effective treatment will be provided. If this proposal is adopted, dangerous mentally ill persons housed in institutions who cannot be treated will be dealt with by the criminal justice system and will either be sent to prisons or other appropriate institutions.

In sum, the model law expands the reach of the mental health system to those who desperately need treatment and contracts its reach to those whom it cannot treat.

Right to Treatment and Right to Refuse Treatment

Legal advocates have focused much attention on the deplorable conditions in public hospitals. Through the courts, they have asserted several constitutional theories from which court rulings have developed constitutional rights for the mentally disabled.

One of the major principles in cases challenging the neglect of patients in state institutions is the right to treatment.

Dr. Morton Birnbaum, a physician and attorney, is recognized as the first person to articulate the theory that a person involuntarily committed to a state hospital has a legally enforceable right to treatment. Writing in the American Bar Association Journal in 1960, Dr. Birnbaum used a quid pro quo argument, essentially saying that when a patient is indefinitely confined to an institution for treatment, it is a violation of substantive due process not to provide treatment. Since then, the constitutional right to treatment has been an issue in many cases, although several states have recognized the right in their

mental health codes. (88)

In 1966, one of the first cases to lend support to the right to treatment was Rouse v. Cameron, 373 F. 2d 451 (D.C. Cir. 1966). Although the case was decided on other grounds, specifically, that the District of Columbia statute recognized that the purpose of involuntary commitment was to provide treatment, the U.S. Court of Appeals acknowledged also that a right to treatment might be found in the U.S. Constitution under the 14th Amendment's due process and equal protection clauses as well as the Eighth Amendment's prohibition against cruel and unusual punishment, if the purpose of involuntary commitment was for treatment and none was given.

The first case to recognize a constitutional right of mental a patient to receive treatment was Wyatt v. Stickney, 325 F. Supp. 781 (M.D. Ala. 1971). In this opinion involving recommitment to Bryce State Hospital in Alabama U.S. District Court Judge Frank Johnson wrote, "the purpose of hospitalization for treatment is treatment. This is the only justification, from a constitutional standpoint, that allows civil commitments to mental institutions such as Bryce...To deprive any citizen of his or her liberty upon the altruistic theory that the confinement is for humane therapeutic reasons and then fail to provide adequate treatment violates the fundamentals of due process." (89)

Although the Supreme Court was presented with "a right to treatment" in O'Connor v. Donaldson, (90) the Court ruled that it was not necessary to decide the difficult issue of this right to treatment, having decided that Donaldson's confinement under

Florida statute simply because he was mentally ill was unconstitutional. The lower court, however, had received considerable evidence that the "Milieu therapy" provided by the Florida State Hospital was nothing more than custodial confinement. In its opinion the Fifth Circuit Court of Appeals stated that a patient had "...a constitutional right to receive such individual treatment as will give him a reasonable opportunity to be or to improve his mental condition" Donaldson v. O'Connor, (91) Again, when the case went to the Supreme Court, the Court specifically declined to address the question of a constitutional right to treatment.

The most recent case to be decided by the Court that involved the treatment of mentally disabled persons was Youngberg v. Romeo, 457 U.S. 307 (1982). While interpretations of Youngberg differ, it is agreed that it provides crucial input on the right to treatment.

The plaintiff in the case, Romeo, was a profoundly retarded and aggressive 33-year-old male, with a mental capacity of 18 months of age, who was involuntarily committed by his mother to Pennhurst State School and Hospital, a Pennsylvania state facility for the mentally retarded.

During his stay at Pennhurst, Romeo suffered injuries - both self-inflicted and inflicted by other patients - on over 70 occasions. The injuries included a broken arm, a fractured finger, injuries to sexual organs, human bite marks, lacerations, black eyes and scratches. His injuries then became infected, either from inadequate medical attention or from contact with

human waste that staff failed to clean up. In addition, Romeo was shackled to a chair or a bed at Pennhurst for long periods of time. The staff claimed it was to control Romeo's aggressive behavior. Romeo's mother believed it was for staff convenience only.

Romeo's mother filed suit in the federal district court on his behalf alleging damages for her son being improperly shackled, the hospital's failure to prevent his abuse, and failure to provide adequate treatment for his mental retardation in violation of his rights under the 8th and 14th Amendments to the Constitution.

Romeo claimed specifically that he had a constitutional right to personal safety, freedom from undue bodily restraints and training or habilitation to ensure that right. The district court ruled that only the 8th Amendment's prohibition against cruel and unusual punishment was applicable to Romeo's circumstance and held against Romeo on that basis. Romeo appealed, and the Court of Appeals ruled that the 14th and not the 8th Amendment was applicable in involuntary commitment proceedings. The Appeals court reasoned that the 8th Amendment protection is limited to persons who are convicted of crimes and the 14th Amendment prohibits deprivation of life, liberty or property by the state without due process of law for all citizens and is therefore the appropriate standard to be applied in involuntary commitment proceedings. The court held that an involuntarily committed person has a constitutional right to safe conditions, freedom from personal restraint, and training to

protect those rights.

The sole question presented to the Supreme Court on appeal, was whether these 14th Amendment protections applied to Romeo. At trial, the state had already conceded that mentally retarded patients have a constitutional right to adequate food, shelter, clothing and medical care under the 14th Amendment.

The Court first considered Romeo's claim to a right to safe conditions. The Court noted that the right to personal security is a protected constitutional right that cannot be extinguished even when one is imprisoned. Thus, if it is constitutionally impermissible to hold convicted felons in unsafe conditions, it is also unconstitutional to hold the involuntarily committed in unsafe conditions. The Court next considered the right to freedom from bodily restraint and again noted that this right has long been recognized.

The Court then considered whether Romeo had a right to training or habilitation to secure these rights. The Court referred to the American Psychiatric Association's brief which defined habilitation as focusing on training and development of needed skills for the mentally retarded. The Court determined that since the rights to safety and freedom of movement were recognized, training to protect these rights is also recognized. Upon holding that involuntarily committed mentally retarded persons have constitutionally protected rights to safe conditions, freedom from undue bodily restraint and habilitation to ensure those rights, the Court had to determine whether the state had violated these rights.

The Court upheld the standard applied by the Court of Appeals, by balancing the individual's interest with the state's interest and held that the Constitution only requires that the courts make certain that professional judgment was exercised at the time the decision was made.

The Court noted that only minimally adequate training as may be reasonable was constitutionally required and concluded that in deciding what is reasonable, courts must show deference to the judgment exercised by a professional.

Despite the fact that the Supreme Court's majority opinion did not address the issue of a general right to treatment in Youngberg, certain observations may be made. First, the fact that this general right was not discussed does not necessarily mean that the Court would not find such a right in another case. Such a right has been found in numerous lower court decisions (92) and the task panel on legal and ethical rights of the President's Commission on Mental Health has observed that "(w)hile the Supreme Court has not directly decided whether there is a constitutional right to treatment..., the overwhelming weight of legal authority is that (at least) all involuntarily confined mental patients have a 'constitutional right to receive such treatment as will given them a reasonable opportunity to be cured or to improve (their mental) condition.'" (93)

Second, the rationale of the majority in Youngberg could be used to support a finding of broad right to treatment. One commentator has noted that the liberty-based rationale used by

Justice Powell in the majority opinion may provide a basis for a broader right to treatment in three ways: (1) Justice Powell's requirement for training necessary to prevent violent or self-destructive behavior could arguably require broad training, such as basic self-help skills, since psychiatric studies apparently indicate that such training reduces violent behavior; (2) the liberty-based rationale could also be used, as was stated in a concurring opinion by Justices Brennan and O'Connor, "to include within the minimally adequate training required by the Constitution...such training as is reasonably necessary to prevent a person's pre-existing self-care skills from deteriorating because of his commitment" (94); and (3) the majority's reasoning could be used to imply rights that protect the patient's interest in release. (95) It was then concluded that "the majority's liberty-based rationale suggests that mental patients have a constitutional right to habilitative rather than merely protective treatment."(96)

Since the Youngberg decision, lower courts have not been consistent. Two opinions which have adhered strictly to the Supreme Court's analysis in Youngberg are Phillips v. Thompson, (715 F. 2d 365) and Society for Goodwill to Retarded Children, Inc. v. Cuomo (737 F. 2d 1239 (2nd Cir. 1984)).

In Phillips, the plaintiff, one of several hundred mentally retarded adults, resided at a privately-owned mentally retarded facility for the mentally retarded under a program sponsored by the State of Illinois. The residents were told of the facility's immediate closing and given 24 hours in which to move.

Representatives of the State Department of Mental Health instructed them to pack their belongings and moved them to state institutions.

Phillips sued the state alleging that his personal freedom was substantially restricted and that he was not receiving adequate rehabilatitive training. The district court ruled against Phillips and held that his liberty of movement was not illegally restricted in violation of the 14th Amendment nor was plaintiff denied training. Phillips appealed and the Court of Appeals affirmed. The court cited Youngberg in upholding the professional judgment standard applied by the lower court. The court determined that Phillips' liberty of movement was limited only by a reasonable requirement of caring for a large number of handicapped people in an institution as such requirements were determined by the professionals who operated the institution.

With respect to training, the court determined that Phillips was receiving adequate training prescribed by professional judgment.

In Society for Good Will, parents and residents of the Suffolk Developmental Center (SDC), an institution which houses mentally retarded persons, filed suit against the state of New York seeking improvement of living conditions, training and education of residents and transfer of residents into community placement. The district court ruled for plaintiffs and in addition, ordered 400 of the 1,200 SDC residents into community settings by 1987. Defendants appealed the entire ruling and order to the Court of Appeals for the Second Circuit. The court

reversed the lower court's decision which had found for the plaintiffs by relying extensively on Youngberg.

With respect to plaintiffs' claim that the state violated their constitutional rights, the court held that, in light of Youngberg, the state must provide safe conditions to its residents, but held that the state did not unduly restrict plaintiffs' freedom of movement by either physical restraints or by failing to provide community placement. The court held that Youngberg in no way intended that mere residence in an institution violated constitutional rights for the mentally retarded. Further, the court cited Youngberg by stating that due process is satisfied if restraints are imposed on the mentally retarded in the judgment of qualified professionals and that courts should defer to this judgment.

With respect to training, the court held that a mentally retarded person has a due process right to training sufficient to prevent him from losing the basic self-care skills he had upon admittance to the institution. The court noted, however, that this does not include a right to training as would improve a resident's basic self-care skills beyond those with which he entered the institution and does not encompass skills that are not basic to self-care.

The decisions in Doe v. Public Health Trust of Dade County 696 F. 2d 991 (11th Cir. 1983), and Scott v. Plante, 691 F. 2d 634 (3rd Cir. 1982) on remand from the Supreme Court 102 S. Ct. 3474 (1982) 696 (F. 2nd 991 11th Cir. 1983) illustrate a broader interpretation of the Youngberg opinion.

In Doe, plaintiffs voluntarily admitted their minor daughter, Jane, to Jackson Memorial Hospital's adolescent psychiatric unit in Florida. At the time of admittance, plaintiffs were told by the hospital staff that they would not be able to communicate with Jane for the purpose of orientation and psychiatric evaluation. The Does consented and after one week attempted to communicate with their daughter. The hospital staff refused them access because Jane had not earned "privileges" of communication as required by her treatment regimen. The Does were also denied information on their daughter's treatment, approximate length of care and any possible side effects of medication. Hospital officials stated that the Does could seek a discharge of their daughter at any time if they did not wish to abide by the hospital's rules. The Does sued alleging that the "no communication rule" was non-therapeutic and medically unsound and that the right to communicate is constitutionally protected and cannot be abridged in exchange for service from the state. The district court ruled against the Does and they appealed. The U.S. Court of Appeals for the 11th Circuit reversed and held in favor of the Does. The court discussed at length the significance of the family and the importance of parental oversight. The court did not question the legitimacy of the professional judgment behind this program and said the program may well cure a patient. The court held, however, that the deference to medical judgment, as recognized in Youngberg, cannot impinge upon the constitutionally recognized parent-child relationship. In addition to these court findings of a broad right to treatment, commentators on the court's opinion in

Youngberg have suggested other ways to interpret the opinion to find a right to treatment. (97)

By setting what is commonly called a "professional judgment" standard for constitutional review of decisions in mental health facilities, to many the clear message of the court was that it would not get involved in the complex issues in only state hospitals. However, the approaches taken by lower courts in subsequent "right to refuse treatment" cases further exemplifies the state of flux that exists in mental health law.

Another major issue for mental patients in institutions concerns the ability or inability to refuse treatment. Because of the important role of drugs in the treatment of the mentally disabled, particularly the mentally ill, and the potential abuse of drugs as a disciplinary substitute for physical restraint and seclusion, the right to refuse treatment, specifically medication, has been called the most controversial subject in institutions and mental health law today. (98) Forms of treatment other than medication have also been at issue in cases involving this right. (99)

Although federal courts recognize mental patients' right to refuse treatment, controversy still centers on how the right should be implemented. The different approaches taken in court opinions interpreting the right typically reflect the classic professional clash in mental health law between the legal and medical professions. Whether a patient may be forced to take medication in an emergency? What constitutes an emergency? Whether the right applies for patients who have been adjudicated

as being incompetent? All of these questions have been raised by courts trying to interprete and establish the parameters of this right.

One commentator has described the origins of the right to refuse treatment as follows:

> "The doctrine can be traced back over two hundred years to an English case in which the King's Court opined that medical surgery performed without consent to the patient constituted a tortuous assault. Modern decisions continue to impose liability for unconsented medical treatment, even where that treatment is, from an objective view, beneficial to the patient. The requirement of consent has long been considered necessary to protect not just the right of self-determination but also the very inviolability of one's person. Thus, treatment without consent constitutes unlawful assault and battery. (100)

The two leading constitutional cases on the right to refuse treatment are Rennie v. Klein (101), and Mills v. Rogers (102).

In both cases, plaintiffs asserted a right to refuse psychotropic medication and the lower courts recognized this right. Both were appealed to the Supreme Court and remanded in light of the Court's decision in Youngberg.

In Rennie, plaintiff, an involuntarily committed mentally ill patient at the Ancora Psychiatric Hospital, a state institution in New Jersey, sued several state officials and hospital personnel alleging that he had a constitutional right to

refuse forcible treatment by antipsychotic drugs, which was violated by the state. The U.S. District Court recognized Rennie's right to refuse treatment in a non-emergency and noted that the final decision should rest with the patient. The court recognized that the constitutional right to refuse cannot be absolute and can be overruled if the patient is endangering himself or other patients.

The decision was appealed to the Third Circuit Court of Appeals which affirmed the district court's opinion in upholding Rennie's right to refuse treatment. The court's analysis included a least intrusive means test. The decision was again appealed to the U.S. Supreme Court. Previously, in Youngberg, the Court held that the standard for determining whether a mentally retarded patient could recover damages against a doctor or other professionals was whether the decision by the professional was such a substantial departure from accepted professional judgment as to show that the decision was unsound. The court did not adopt the least intrusive means standard of the appellate court, but instead remanded Rennie back to the panel for reconsideration in light of the Youngberg decision.

Upon reconsideration, the court of appeals held that Rennie had a constitutional right to refuse antipsychotic drug treatment and rejected the least intrusive means test because of Youngberg. But it may be constitutionally administered if in the exercise of professional judgment, such treatment is necessary to prevent the patient from endangering himself or others. The professional decision is presumed valid unless it is shown to be a substantial

departure from the norm. The court accepted the professional judgment standard enunciated in Youngberg and added that the professional, in making his decision, should consider possible side effects to patients.

In Rogers, plaintiff and other involuntarily committed mentally ill patients at the Boston State Hospital in Massachusetts filed suit in U.S. District Court against state officials and hospital staff seeking to enjoin defendants from forcibly medicating plaintiffs with antipsychotic drugs against their will. The court ruled for plaintiffs and in making its decision, differentiated between two classes of plaintiffs -- those adjudicated incompetent and those who were not -- and two types of settings -- emergency and nonemergency situations. The court held that involuntarily committed mentally ill patients who were not adjudicated incompetent have a constitutional right to refuse treatment absent an emergency but may be forcibly medicated in emergency situations. An emergency was defined as a situation where there was a substantial likelihood of harm. Mental patients who have been adjudicated to be incompetent have a constitutional right to refuse treatment but the decision must be made by a guardian using a substituted judgment standard. A substituted judgment is generally considered to be a decision that an incompetent person would make for themselves if they were competent and is based upon the individual's religious beliefs and previously expressed opinions. The court noted here also that forcible medication was allowed in emergency situations.

The decision was appealed to the First Circuit Court of Appeals which affirmed in part and reversed in part. The appeals court held that involuntary commitment to a state institution does not preclude a patient's competency to make treatment decisions thus, a mentally ill patient has a constitutional right to refuse treatment through the use of anti-psychotic drugs. The court held, however, that in emergency situations, the physician could forcibly treat the patient if the physician exercised good professional judgment. The court defined an emergency to include situations where forced treatment was necessary to prevent substantial deterioration of the patient's mental illness.

The decision was appealed to the Supreme Court which remanded to the Court of Appeals. The court was instructed to determine the rights of the patients under state law which, the Supreme Court believed, gave adequate protection. The Court of Appeals in turn remanded to the Massachusetts Supreme Judicial Court to determine state law. The Massachusetts Supreme Court determined that, based upon state law, a mentally ill patient not adjudicated incompetent had a right to refuse antipsychotic drugs in a nonemergency. In an emergency, a physician could forcibly medicate a patient if medication is necessary to prevent imminent and substantial deterioration of mental health. The court further noted that a mentally ill person adjudicated incompetent had a right to refuse treatment, absent an emergency, exercised through a substituted judgment made by a judge. In an emergency, the decision to forcibly medicate is left to the discretion of the hospital staff.

The decision was again appealed to the Court of Appeals which held that the rights enunciated by the Massachusetts Supreme Court exceeded constitutional requirements although the court did not state what constitutional protection was recognized. The court noted that the substituted judgment can be made by a physician and not a judge and that a physician could forcibly medicate a patient if the physician believes the interests of the state outweigh the interests of the individual.

Since the Rennie and Rogers decisions, federal courts have been divided between medical and legal expertise in the right to refuse treatment, although the majority of cases appear to defer to medical judgment.

For example, in Project Release Provost, 722 F. 2d 960 (2d Cir. 1983), the Second Circuit found that a procedural scheme must allow for sufficient opportunity for professional input. In U.S. v. Leatherman, 580 F. Supp. 977 (D.D.C. 1983) a patient committed to St. Elizabeths Hospital in Washington, D.C. after a finding of not guilty by reason of insanity, was found to have a qualified right to refuse treatment. In deferring to medical judgement the court observed that "to require the courts to pass on such issues would embroil them in a never-ending controversy concerning medical judgments for which courts have neither the institutional resources nor the necessary expertise." (103)

Some other courts have taken guidance from the Supreme Court in Youngberg v. Romeo, in setting the parameters of the right to refuse treatment. For example, in Johnson v. Silvers, 742 F. 2d 823 (4th Cir. 1984), the court deferred to medical judgment. The

Court of Appeals found that an allegation that an involuntarily committed mental patient was being forced to take medication against his will constituted a claim actionable under 42 U.S.C. 1983 since such action gave rise to a protectible liberty interest. This liberty interest was found to be limited by the Supreme Court's holding in Youngberg, and in order to prevail the court found that the plaintiff must show that the defendant "has required him to take anti-psychotic drugs without exercising professional judgment."(104)

But, a few courts have required more extensive judicial involvement. For example, in Colorado v. Medina, 662 P. 2d. 184 (Colo. Ct. App. 1983), the court found that in the absence of an emergency, an involuntarily committed mental patient could not be given forcible medication without a court order.

In addition to the controversy over to what extent medical judgments should be deferred to, other issues have also given rise to controversy in cases discussing the right to refuse treatment. As was noted in several of the cases discussed above, generally, forcible medication has been allowed where there is an emergency situation. The cases have differed, however, as to what constitutes an emergency. Some cases, like the original district court decision in Rogers have defined emergency to mean a substantial likelihood of harm. Other cases, like the first court of appeals decision in Rogers, have used a broader definition of emergency to include the balancing of the patient's interests with those of the state.

In a situation very close to that of emergency treatment,

courts have also dealt with the issue of whether a mental patient who has been determined to be dangerous to himself or others has a right to refuse treatment. Some courts have found that if a patient is determined to be dangerous, medication can be constitutionally administered without the patient's consent. For example, in Weiss v. Missouri Department of Mental Health, 587 F. Supp. 1157 (E.D.Mo. 1984), the district court found "a voluntary patient who presents a danger to himself or others has no constitutional right to refuse medication." (105)

Another issue where courts have differed concerns the decision to refuse or accept treatment if the patient has been declared incompetent. Generally, judicial decisions are split into two views. One view is that the decision should be made by an informed person such as a physician; the other is that the substituted judgment standard, i.e., what would the patient want if he or she were competent to decide, should be used. It should be noted that in either of these views, the person making the judgment could be a guardian, physician, or court.

A pending case on the treatment issue, Halderman v. Pennhurst, involves questions concerning whether a right to treatment or habilitation in the least restrictive alternative exists under federal statutes or the U.S. Constitution. The procedural history of this case has been complicated, (106) and it is presently on remand from the U.S. Supreme Court to the third circuit court of appeals. In connection with this remand, the Department of Justice filed a brief with the third circuit alleging that the district court erred in finding that the

plaintiffs have a federal right to treatment in the least restrictive alternative. The brief reflects a change from the Department of Justice's previous postion.

The Department of Justice brief in Pennhurst framed the issue as "whether federal law provides involuntarily committed mental health patients a substantive right to 'habilitation' and, if so, whether the State must provide such habilitation in the least restrictive setting."(187) The Department of Justice brief argued that there is no substantive constitutional right to habilitation for involuntarily committed mental health patients beyond "the limited training right recognized in Romeo."(188) In addition, the brief contended that even if such a right were allowed, the least restrictive alternative analysis of the district court should not be allowed since in Youngberg the Supreme Court found that professional judgments are entitled to judicial deference. These two contentions will be discussed separately.

First, the Supreme Court has not addressed the issue of whether a mentally retarded person who is involuntarily committed to a state institution has a general constitutional right to treatment or habilitation. The closest the Court has come has been its holding in Youngberg that the state is under a duty to provide a mentally retarded institutionalized person "with such training as a appropriate professional would consider reasonable to ensure his safety and to facilitate his ability to function free from bodily restraints." (189) Thus, the position taken in the Department of Justice brief that there is not a general right

to treatment in the least restrictive alternative is not directly contradictory to Supreme Court holdings. However, as was discussed previously, numerous lower court decisions have found that there is a general constitutional right to treatment in the least restrictive alternative. In addition, such holdings would not appear to be inconsistent with the Supreme Court's decision in Youngberg. As noted above, the liberty-based rationale used by the majority in Youngberg could be used to require broad rights in training such as basic self-help skills, prevention from deterioration and rights to protect the patient's interest in release.(110) The Department of Justice brief noted that its argument that there was no general right to treatment was based "[l]argely for the reasons articulated by Chief Justice Burger in his concurring opinion in Romeo."(111) The Chief Justice found in his concurrence that "...even if respondent could demonstrate that the training programs at Pennhurst were inconsistent with generally accepted or prevailing professional practice -- if indeed there be such -- this would not avail him so long as his training regimen was actually prescribed by the institution's professional staff." (112) The reasoning used by the Chief Justice was not accepted by the Court as a whole, although it should also be noted that the majority did not specifically reject this argument. The Department of Justice's reliance on such reasoning is, then, arguably not contrary to the Supreme Court's holding but neither is it required by the majority's opinion.

In Youngberg, the Supreme Court adopted the standard articulated by Chief Judge Seitz in his concurring opinion in the

court of appeals decision in Youngberg that "the Constitution only requires that the courts make certain that professional judgment in fact was exercised. It is not appropriate for the courts to specify which of several professionally acceptable choices should have been made." (113) Thus, the Court appears to have rejected the least intrusive means standard and the brief of the Department of Justice apparently relies on this language to mean that "[o]nce appropriate state authorities make that decision as an exercise of professional judgment, the decision is not rendered constitutionally infirm because a less restrictive 'community placement' alternative may have been available but not chosen."(114)

Although the Supreme Court's language would appear to limit the concept of the least restrictive alternative, at least as applied to the right to treatment, the restrictive interpretation given the language in the Department of Justice's brief is not necessarily the only possible interpretation. In Rennie v. Klein, 720 F.2d 266 (3d Cir. 1983), the third circuit found that if it were to consider its previous opinion in Rennie (115) in light of Youngberg (as required by the Supreme Court), (116) the concept of the "least intrusive means" could not be employed. However, the same result, that is, a right to refuse anti-psychotic drugs, was obtained by the third circuit's majority using the professional judgment standard and noting that the extent to which the patient will suffer harmful side effects is one of the factors to be considered with the use of professional judgment. In a concurring opinion in Rennie, it was emphasized that although professional judgment is entitled to

deference, such judgment "provides primarily a starting point for defining the constitutional rights at stake...The professional judgment of a physician acting with the power of state authority requires more than comparable professional decisions in a voluntary doctor-patient relationship. In the case of the forcible use of antipsychotic drugs, a state-employed physician must, at the very least, consider the side effects of the drugs, consult with other professionals and investigate other options available before that physician can be said to have discharged full professional judgment." (117)

In another recent decision, the second circuit in Woe v. Cuomo, No. 83-7269, No. 332 (2d Cir. Feb. 22, 1984), analyzed the meaning of deference to professional judgment as discussed in Youngberg and found that accreditation of a facility was an "exercise of professional judgment" entitled to deference under Youngberg. However, deference was not interpreted to mean that a court was barred from probing behind such accreditation. "Youngberg did not suggest that the judgment of the state's professionals was necessarily conclusive. On the contrary, the Court indicated that the testimony of Romeo's experts should have been admitted as relevant to the professional acceptability of the training he was receiving." To the extent, then, that the arguments in the Department of Justice's brief imply that courts lack the ability to look behind any professional judgment, these arguments would appear to be at odds with the recent cases of Rennie and Woe.

Summary

The Supreme Court in Youngberg v. Romeo, 457 U.S. 307 (1982), found that the state is under a duty to provide a mentally retarded institutionalized person "with such training as an appropriate professional would consider reasonable to ensure his safety and to facilitate his ability to function free from bodily restraints." (118) However, the Supreme Court's majority opinion did not go beyond this limited holding to consider whether there is a general right to treatment. The court did find that in determining what is reasonable, the courts are to show deference to the judgment of a qualified professional. In the remand of Halderman v. Pennhurst, the Court of Appeals for the Third Circuit was asked to address the issue of whether there is a right to treatment or habilitation in the least restrictive alternative based on federal statutes or the U.S. Constitution. In connection with this remand, the Department of Justice filed a brief alleging that there was no federal right to treatment in the least restrictive alternative. The arguments in the Department of Justice's brief were based on its analysis of Youngberg v. Romeo and relied on the reasoning presented in Chief Justice Burger's concurrence.

Although the arguments presented by the Department of Justice do not appear to directly contradict the Supreme Court's holding in Youngberg, they are a restrictive interpretation of the case and one which is contrary to arguments presented by commentators and several recent judicial interpretations. Previous to Youngberg, numerous courts had found a right to

treatment for mental patients. In addition, the liberty-based rationale used to arrive at the majority's holding in Youngberg could be used to require broad rights in training, such as basic self-help skills, prevention from deterioration and rights to protect the patient's interest in release. Such reasoning finds support in the concurring opinion by Justice Blackmun in Youngberg.

The Supreme Court in Youngberg apparently set some limits on the least restrictive alternative theory by its emphasis on deference to professional judgments. However, the exact parameters of such deference are not clearly delineated in Youngberg. The Department of Justice brief interprets this deference to mean that once appropriate state authorities make a professional judgment decision, the decision is not unconstitutional because a less restrictive community placement might have been chosen. The restrictive interpretation given to the Supreme Court's language by the Department of Justice is not the only possible interpretation. Several recent cases have discussed the Youngberg requirement of deference to professional judgment and have found that it "provides primarily a starting point for defining the constitutional rights at stake..."(119)

In summary, then, the arguments made by the Department of Justice's brief in Pennhurst would not appear to be compelled by the Supreme Court's decision in Youngberg. They are one possible interpretation and can be described as a restrictive interpretation which could arguably be contrary to several recent judicial interpretations of Youngberg as well as contrary to the interpretation given Youngberg by some commentators.

FOOTNOTES

1. Governor's Task Force on Health and Safety at Cleveland Psychiatric Institute, State of Ohio, June 22, 1984, p. 28.

2. Joe Stebbins and Diana Dawson, "Mental Health in Missouri: A State of Stress", The Kansas City Star, Dec. 11, 1983, p. 21A.

3. Tina Lam, "Foreign-born doctors spark complaints about patient care," Ann Arbor News, Jan. 17, 1984.

4. Robert L. Pierce and Mike King, "Who cares for Kentucky's mentally ill?" Louisville Courier-Journal, Dec. 29, 1983, p. E7.

5. Robert D. Miller, M.D., Ph.D., "Public Mental Hospital Work: Pros and Cons for Psychiatrists", Hospital and Community Psychiatry, Vol. 35, (September, 1984) p. 930.

6. R.A.J. Review Panel, Third Report to the Court, May 1, 1983 - Nov. 1, 1983, 800 E. 8th St., Austin, Texas, pp. 28, 35.

7. R.A.J. Review Panel, Fifth Report to the Court, June 1, 1984 - Nov. 1, 1984, 800 E. 8th St., Austin, Texas, p. 14.

8. Governor's Task Force on Health and Safety at Cleveland Psychiatric Institute, State of Ohio, June 22, 1984, p. 29.

9. Clarence J. Sundram, J.D., "Obstacles to Reducing Patient Abuse in State Institutions," Hospital and Community Psychiatry, Vol. 35 (March 1984), p. 242.

10. Psychotherapeutic Drug Use: A Rx for Improvement--A Study of Selected New York State Psychiatric Centers, New York State Commission on Quality of Care for the Mentally Disabled, August 1983.

11. C. Thomas Gualtieri, M.D., and Robert L. Sprague, Ph.D., "Preventing Tardive Dyskinesia and Preventing Tardive Dyskinesia Litigation," Psychopharmacology Bulletin, Vol. 20, No. 3, (1984), p. 346.

12. In the matter of Christopher Dugan. A patient at South Beach Psychiatric Center, The New York State Commission on Quality of Care for the Mentally Disabled and the Mental Hygiene Review Board, January 1985, p. 12 and Attachment 1.

13. "Seclusion, Restraint Still Important Tools, Task Force Concludes," Psychiatric News, March 1, 1985, p. 1.

14. Roger Morris et al, "The officials are the last to know," Santa Fe Reporter, Aug. 29, 1984, p. 6.

15. A Review of Living Conditions in Nine New York State Psychiatric Centers, May 1984, New York State Commission on Quality of Care for the Mentally Disabled, December 1984, p. X.

16. Wyatt v. Ireland, No. 3195-N, M.D. Ala., Brief for Plaintiffs and Plaintiff-Intervenors , filed October 26, 1982, at 15.

17. Robert D. Miller, M.D., Ph.D., "Public Mental Hospital Work: Pros and Cons for Psychiatrists," Hospital and Community Psychiatry, (September 1984), p. 931.

18. Paul B. Lieberman, M.D., and Boris M. Astrachan, M.D., "The JCAH and Psychiatry: Current Issues and Implications for Practice," Hospital and Community Psychiatry, Vol. 35, (December 1984), p. 1209.

19. John H. Houck, M.D., "Regulation and Accreditation: The Pros and Cons for Psychiatric Facilities," Hospital and Community Psychiatry, Vol. 35, (December 1984), p. 1202.

20. Wyatt v. Ireland supra note 16 at 12-13.

21. Penny Barker, Project Officer, Health Standards and Quality Bureau, Health Care Financing Administration, Alvira B. Brands, Project Officer, National Institute of Mental Health, and Task Force Work Group composed of representation from Health Standards and Quality Bureau, and National Institute of Mental Health consultants, Interpretative Guides for Medicare/Medicaid Surveys, April 1980, p. 4.

22. Wyatt v. Ireland supra note 16 at 29.

23. Id at 36.

24. Public Law 97-35, Sec. 2176.

25. 46 C.F.R. 48535, October 1, 1981.

26. 42 U.S.C. 1997 et seq.

27. Senate Judiciary Committee Report to accompany S. 10, Sen. Rept. No. 96-415, 96th Cong. Sess., p. 1, and House Conference Rept. No. 96-987, p. 8.

28. 325 F. Supp. 781 (M.D. Ala. 1971), hearing on standards ordered, 324 F. Supp. 1341 (M.D. Ala. 1971), enforced, 344 F. Supp. 373 (M.D. Ala. 1974) aff'd sub nom. Wyatt v. Aderholt, 503 F. 2d 1305 (5th Cir. 1974), institutions placed in receivership, Wyatt v. Ireland, No. 3195-N (M.D. Ala. Oct. 25, 1979).

29. 357 F. Supp. 752 (E.D. N.Y. 1973).

30. Supra, note 13, at 2.

31. 419 F. Supp. 358 (D.Md. 1976), aff'd, 563 F.2d 1121 (4th Cir. 1977).

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92. See e.g., Wyatt v. Stickney, 344 F Supp. 387 (M.D. Ala. 1972); aff'd in part, rev'd and remanded in part sub nom. Wyatt v. Aderholt, 503 F. 2d 1305 (5th Cir. 1974); Nichols v. Laymon, 506 F. Supp. 267 (N.D. Ill. 1980). It should be noted that some cases have attempted to limit the right to treatment with regard to voluntarily confined mental patients or to institutionalized retarded children. See, e.g., Harper v. Cserr, 544 F. 2d 1121 (1st Cir. 1976).

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94. Youngberg v. Romeo, 457 U.S. 307, 327 (1982).

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99. See "Limiting the Therapeutic Orgy: Mental Patients' Right to Refuse Treatment," 72 NWUL, Rev. 461.

100. Legal Rights, ibid., p. 28.

101. 462 F. Supp. 1131 (D.N.J. 1978) (on motion for preliminary injunction); 476 F. Supp. 1295 (D.N.J. 1979) (classwide preliminary injunction); aff'd in part, modified in part, and remanded 653 F. 2d 836 (3d Cir. 1981); vacated and remanded for consideration in light of Youngberg v. Romeo, 457 U.S. 307, (1982), 458 U.S. 1119 (1982); 720 F. 2d 266 (3rd Cir. 1983).

102. (Originally titled Rogers v. Okin), 478 F. Supp. 1342 (D. Mass. 1979); aff'd in part, rev'd. in part, vacated in part and remanded sub. nom. Mills v. Rogers, 457 U.S. 291 (1982); Rogers v. Commissioner of the Department of Mental Health, 390 Mass. 489, 458 N.E. 308 (Mass. Supp. Jud. Ct. 1983); Rogers v. Okin, 738 F. 2d 1 (1st Cir. 1984).

103. 580 F. Supp. 977, 979 (D.D.C. 1983).

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105. 587 F. Supp. 1157, 1161 (E.D. Mo. 1984).

106. The litigation began in 1974 and after a lengthy trial the district court found constitutional and statutory violations. 446 F. Supp. 1295 (E.D. Pa. 1977). On appeal, the third circuit affirmed most of the district court's judgment but based its decision on the bill of rights provision of the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. 6010. 612 F. 2d 84 (3rd Cir. 1979). The case was remanded to the district court for consideration of which patients could be served in community living arrangements. On appeal to the U.S. Supreme Court, the court of appeals' decision was reversed and remanded to determine if the order could be based on state law, the constitution, or section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794. 451 U.S. 1 (1981). On remand, the court of appeals affirmed its prior judgment in its entirety based on state law. 673 F. 2d 647 (1982). When the case went back up to the U.S. Supreme Court, the Court again reversed and remanded holding that the Eleventh Amendment prohibited the district court from ordering state officials to conform their conduct to state law. The Court found that on remand the court of appeals was to consider to what extent the district court decision could be based on the Eighth and Fourteenth amendments to the U.S. Constitution, section 504 of the Rehabilitation Act and other sections of the Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. 6011, 6063.

107. Halderman v. Pennhurst, Nos. 78-1490, 78-1564, 78-1602, Brief for the United States, filed April 24, 1984, at 7. (Herafter referred to as DOJ brief.)

108. Id., p. 8.

109. Youngberg v. Romeo, 457 U.S. 307, 324 (1982).

110. Few cases since Youngberg have specifically addressed the issue of the right to receive treatment although several have discussed deference to professional judgment. In Phillips v. Thompson, 715 F. 2d 365 (7th Cir. 1983), the seventh circuit found that "...Youngberg teaches that, at the most, the class members were entitled to minimally adequate training as is reasonable in the light of their interest in freedom of movement and that deference must be shown to the professional judgment of those directing the operation of the institution." This statement was not elaborated on by the court although it seems to indicate that the seventh circuit would interpret Youngberg in a more restrictive manner than commentators have suggested.

111. DOJ Brief at 7.

112. Youngberg v. Romeo, 457 U.S. 307, 331 (1982).

113. Id. at 321, citing 644 F. 2d at 178.

114. DOJ Brief at 11.

115. Rennie v. Klein, 653 F. 2d 836 (3d Cir. 1981).

116. Rennie v. Klein, 102 S. Ct. 3506 (1982).

117. Rennie v. Klein, 720 F. 2d 266, 271-272 (3d Cir. 1983).

118. Youngberg v. Romeo, 457 U.S. 307, 324 (1982).

119. Rennie v. Klein, 720 F. 2d 266 (3d Cir. 1983).